An Exploration of the Cardiac Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and their Family Caregivers – A Qualitative Study

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AUTHOR'S DECLARATION

I declare that:

- While registered as a candidate for the University's research degree, I have not been a registered candidate or enrolled student for another award of the University or other academic or professional institution.

- No material contained in this thesis has been used in any other submission for an academic award.

- The thesis submitted is entirely my own work and based on my own research; that all sources used are appropriately acknowledged and that where the words of others are used these are clearly placed in quotation marks.

Signature of Candidate:

Rifat Sharif

Date: 21st September 2020

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ABSTRACT

INTRODUCTION/BACKGROUND

Chronic heart failure is a complex condition characterised by loss and disabling symptoms, which sufferers and health care professionals have struggled to understand and manage. Previous and current studies have focused on several cultures as opposed to the proposed study in which Pakistanis of mixed gender were invited to participate. In Western society, there has been an emergence of active and informed patients, with contemporary patients increasingly involved in decisions about their treatment and care. It has been acknowledged that the vast majority of chronic disease management is through self-care and effective self-management. This is also known to reduce resource demand. However, there has been comparatively little research on the concept of the expert self-managing patient within the Pakistani heart failure population. Little was known of the impact and subjective experience of heart failure within Pakistani communities and the issues of caring for patients.

This study was undertaken in response to concerns establishing deficiencies in knowledge of cardiac rehabilitation amongst Pakistani heart failure patients and their family caregivers. No previous investigation had explored this in detail. As part of the present study, it was important to understand and consider the cultural perspective of Pakistani groups, in both a sensitive and appropriate manner, in order to address the needs of this specific Pakistani population in an advanced Western country, where both mortality and morbidity were rising, and ethnic populations were being failed.

AIM OF THE STUDY

The aim of the current study was to explore patient experiences following diagnosis of heart failure in order to identify barriers and facilitators of management, and access to cardiac rehabilitation services. Moreover, it was anticipated that in collaboration with heart failure patients, family caregivers, and healthcare professionals, the development and recommendations of a culturally sensitive tool for Pakistani patients and their family caregivers living with heart failure would be proposed.

OBJECTIVES OF THE STUDY

The objectives of the study were to elicit cultural definitions of heart failure and the impact this had on accessing services for both patients and their family caregivers.

METHODS

Following ethical approval, this qualitative study utilised Strauss and Corbin's (1998) approach to Grounded Theory. A two-phase continuum 12 weeks apart described the experiences of one-to-one interviews, which were conducted with a purposive sample of 18 heart failure patients post discharge following diagnosis of heart failure. Furthermore, nine family caregiver interviews were held (post-interview with patients) in addition to a focus group discussion with a multi-disciplinary team of healthcare professionals. Data collection and analysis were iterative and followed theoretical sampling principles.

FINDINGS

'Battling the culture and ethnic sensitive obstacles of cardiac rehabilitation' was the generated emerging theory of the present study. Emerging from the current study was a substantive theory in which the absence of accessing culturally appropriate and ethnic sensitive tailored cardiac rehabilitation was identified as the main obstacle facing Pakistani heart failure patients and their family caregivers. These struggles acted as the basic social processes of how Pakistani heart failure patients and their family caregivers self-managed. Core categories to emerge from data amplified struggle, limited understanding and uncertainty. Struggle pertained to language barriers and poor access to service provision. Limited understanding was exacerbated by intervening variables, including lack of contact with health professionals and a poor satisfaction of provision to medical care. Uncertainty arose within self-care and poor understanding of knowledge enabling sophisticated management. The properties, conditions, and consequences of struggle, limited understanding and uncertainty were explicated in the development of a theory, supportive of care for Pakistani heart failure patients and their families. The developed theory uncovered in this study conceptualised the major categories to concepts in theory development as it underpinned and recognised the need for a negotiated pathway to self-management. Healthcare professionals together with Pakistani heart failure patients must negotiate the process of recovery by entwining culture, ethnicity and faith. Without the understanding of such imperative mechanisms in place, the functional rehabilitation and lifestyle development of health and recovery including organisational, infrastructural, situated and gendered experience factors weakened the journey of the

Pakistani heart failure patient and family caregiver. These findings had implications for health professionals' practice and cardiac rehabilitation programme improvement and a policy priority for government.

DISCUSSION

A storyline was described that illustrated the journey of living with chronic heart failure exploring the barriers and enablers of effective cardiac rehabilitation. Recommendations for policy and practice were generated that included acknowledgement of the Pakistani heart failure patients' and family caregivers' needs beyond the medically idealised type. It was suggested that a move away from the rigid content and delivery style would promote a greater focus on the subjective experience of chronic illness with an emphasis on culturally sensitive and appropriate tailored delivery.

CONCLUSION

This study assisted the understanding of managing the needs of Pakistani chronic heart failure patients and their family caregivers. The present study has brought to the forefront unique religious, cultural and ethnic values upon which the Pakistani population commands a bespoke platform that requires improved efficacy of health promotion and a re-evaluation of the effectiveness of knowledge management interventions. In addition, it has enriched the understanding and communication of health care professionals; thereby, facilitating encounters characterised by greater support and empathy for individuals living with chronic heart failure in both the capacity of a patient and family caregiver.

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1 CHAPTER ONE: INTRODUCTION AND OVERVIEW

The purpose of this chapter is to provide the historical background to the research study and to justify the need for such a study. An overview of the thesis structure and content will also be provided.

1.1 BACKGROUND

Chronic heart failure (HF) is a condition in which a problem with the structure of the heart impairs its ability to supply sufficient blood flow to meet the body's needs (Neubauer, 2007; Dorland's Medical Dictionary). Patients with heart failure have multiple readmissions to hospital, poor prognosis and a varying quality of life (Krumholz et al, 2002; McAlister et al, 2004; McMurray et al, 1993, 2004; Naylor et al, 2004). Living with heart failure is a complex, dynamic process for both patients and caregivers. It involves multiple challenges including coping with frightening symptoms and complex medications, with depression and anxiety and a loss of role and functional abilities. This can result in a poor quality of life (Stewart et al, 2002). Common causes of HF include myocardial infarction (heart attacks) and other forms of ischemic heart disease, hypertension, valvular heart disease, and cardiomyopathy (Jessup et al, 2009).

Individuals with HF will experience a number of symptoms such as shortness of breath (typically worse when lying flat), which is called orthopnea, coughing, chronic venous congestion, ankle swelling, and exercise intolerance. It has various diagnostic criteria, and the term heart failure is often incorrectly used to describe other cardiac-related illnesses, such as myocardial infarction (heart attack) or cardiac arrest. Treatment commonly consists of lifestyle measures such as smoking cessation, undertaking regular light exercise, decreased salt intake (and other dietary changes), taking a range of medications and sometimes devices or even surgery. Aetiological factors involved in the development of congestive heart failure include hypertension, diabetes, and ischaemic heart disease, all of which differ in prevalence, and possibly mechanisms, between patients of differing ethnic groups (sic) (Lip et al, 2004).

Lip et al (2004) identified that the levels of knowledge and perceptions of HF and the treatments offered for this condition to patients who were attending heart failure clinics in two teaching hospitals within Birmingham, which serves a wide multi-ethnic population, were poor. Results showed that 64.7% (n=22) of South Asian patients felt that God/fate controlled their health whilst 35.7% (n=15) of white patients felt that the greatest factor influencing their health was a health professional. A total of 68 patients of the total cohort of 103 patients (66%) were aware of their primary diagnosis. Half of the South Asian population (17 patients) felt that their condition was not severe in comparison to nine Afro-Caribbean and eight white population patients (40.9% and 19.1%). Of the study cohort, 38 (36.9%) were taking their medicine as it was a prescribed measure by their doctor, a common response of South Asian patients. A majority of South Asian and African-Caribbean patients felt that they did not know or have enough information concerning their medicines and a minority of the African-Caribbean patients felt that they did not adhere to their medicines, contrary to the white population who felt that they were informed of their medication (21.4%/ n=9).

The above study has highlighted a serious deficiency in the knowledge of HF among patients from ethnic minorities; it has demonstrated a need for further investigation. It has been the only study to be conducted in the West Midlands (UK) that focused on the importance of minority ethnic patients' perceptions of illness and management. It is essential therefore to invest more in educating patients from minority backgrounds with regard to the causal factors, symptoms, treatment and rehabilitation processes associated with HF as evidence has shown clearly that these groups are at high risk of developing such a chronic and disabling condition. A greater understanding of knowledge and disease perceptions among non-white populations may be the key to improving management of HF in minority groups. Indeed, ethnicity is an important factor especially if language difficulties are involved (Ziguras et al, 1999; Hellman et al, 1997). The views of family and friends, societal pressures, and a patient's own cultural or ethnic background also influence compliance. Therefore, it has been suggested that these views be investigated further to enhance management of patients.

The above findings found consistency with data from North America and elsewhere where it was reported that knowledge on self-care was deficient in a diverse sample of HF patients, especially in relation to heart failure medications, weight monitoring, and the correct definition of heart failure. They also found that heart failure knowledge scores were uniformly low across gender and racial groups (Artinian et al, 2002). García Gómez et al (2003) also reported that HF patients had poor information about dietary and medical treatment due to poor knowledge and understanding of their condition.

Within South Asian communities, the elderly and women were more likely to leave their treatment in the hands of others rather than take responsibility for themselves (Aslam et al, 1979; Nadar et al, 2003). Reports on ethnic differences in perception of atrial fibrillation (Lip et al, 2002) identified that nearly half of the patients from all ethnic groups said that they took Warfarin because their doctor told them to and were unaware of the actual benefits of this drug. Indeed, South Asians tended to leave a lot of the control of their health to 'God/faith'

(Vaccarino et al, 2002; Nadar et al, 2003) and this belief influenced their compliance and willingness to find out more about their illness and the medication that they took.

Studies have highlighted important deficiencies in the knowledge of HF among patients from ethnic minority groups, as well as deficiencies in the information delivered to these patients. There is a clear and paramount need to invest more in patient education for HF, with special emphasis on certain high risk subgroups, including ethnic minorities (Lip et al, 2004).

A keen interest into the exploration of ethnic minority groups arose from a previous employment as a research assistant. My research within the area of coronary angioplasty raised concerns and interests alike. Patients and their family caregivers recognised many issues pertaining to the comprehension and daily management of diagnosis and a genuine struggle lent itself to conflict within ethnic, religious and cultural factors demanding further insight and consideration of such challenges (Astin et al, 2009, 2010, 2011, 2014). Pakistani patients and their family caregivers specifically experienced constant tensions and strain throughout the project highlighting the need to delve further in on the unmet needs and challenges patients faced subsequently. I felt it was an important objective of the current study to recognise such difficulties with the view of understanding the Pakistani populations ‘reality’ in which they built a platform of rehabilitation. The value of being an ‘insider’, with a shared identity, would enable one to hone such issues aiding a rapport with the view of potentially raising awareness and addressing the deficiencies and gaps of knowledge within the Pakistani population.

Little is known about the impact of heart failure and the subjective experience of heart failure and issues of caring within Pakistani communities. Current studies have focused on sub-continents accounting for several cultures, languages and practices as opposed to the proposed project in which Pakistanis of mixed gender will be invited to participate. The proposed study has been unique in that it explored, via qualitative means, Pakistani HF patients and their family caregivers’ needs, which as stated have clearly not been addressed thus far. As part of the study, it was important to understand and consider the cultural perspective of the Pakistani groups in both a sensitive and appropriate manner in order to tackle issues of:

- Poor support and access
- Problems of ethnicity
- Language barriers
- Problems of communication and understanding
- Social status

with a view to addressing the needs of this specific Pakistani population in an advanced Western country where both mortality and morbidity were rising and ethnic populations were being failed. The current proposed project has aimed to identify and elaborate the needs of the Pakistani population in an under-researched area of heart failure and has offered the opportunity to address the unmet health needs and provide tailored patient information.

An exciting opportunity to unveil pertinent gaps within the Pakistani population will likewise unravel many issues with a very close interest, which in turn would assist better service provision.

British Pakistanis also known as Pakistani British people or Pakistani Britons are citizens or residents of the United Kingdom whose ancestral roots lie in Pakistan. This includes people born in the UK who are of Pakistani descent, and Pakistani-born people who have migrated to the UK. The majority of British Pakistanis originate from the Azad Kashmir and Punjab regions, with a smaller number from other parts of Pakistan including Sindh, Khyber Pakhtunkhwa and Balochistan. The UK is home to the largest Pakistani community in Europe, with the population of British Pakistanis exceeding 1.17 million. British Pakistanis are the second largest ethnic minority population in the United Kingdom and also make up the second largest subgroup of British Asians.

1.2 AIM OF THE STUDY

The aim of the current study was to explore the experience of patients of Pakistani heritage following diagnosis of heart failure in order to identify barriers and facilitators to management and access to rehabilitation services. Moreover, it was anticipated that in collaboration with patients, family caregivers and healthcare professionals the development of a culturally sensitive tool for Pakistani patients and their family caregivers living with heart failure would be proposed.

1.3 OBJECTIVES

The objectives of the study were to:

- Elicit cultural definitions of heart failure and discuss the impact these have on accessing services for both patients and their family caregivers.
- Gain an understanding of the barriers and facilitators in accessing cardiac rehabilitation.

- Understand the issues regarding self-management and service access of HF which Pakistani patients and their family caregivers face.

The emerging results from this study would help propose recommendations for an appropriate intervention for Pakistani HF patients and family caregivers.

1.4 NATURE OF THE STUDY

Qualitative research provides rich descriptions of complex phenomena tracking unique or unexpected events illuminating the experience and interpretation by actors with widely different stakes and roles; giving voice to those whose views are rarely heard and or acknowledged. Initial explorations are developed to generate theories moving towards explanations through the use of in-depth interviews, observations, case study research, focus groups, and ethnography. Therefore, to say that to generate a hypothesis about the patterns one will find before exploring the patterns would lead to bias in the evaluative lens of study and this is not deemed appropriate unlike quantitative research (Richie et al, 2003). In qualitative research a hypothesis is used in the form of a clear statement concerning the problem to be explored, contrary to quantitative research where a hypothesis is developed to be tested. Qualitative research is not designed for hypothesis testing, rather it is designed to explore an area that can later be hypothesis tested with a quantitative approach (or alternately, it can be used to explore the meanings of quantitative answers in more detail).

Grounded theory methodology is a systematic generation of theory from data that contains both inductive and deductive thinking (Strauss & Corbin, 1998). However, when applying the grounded theory method, the researcher does not formulate the hypotheses in advance since pre-conceived hypotheses result in a theory that is un-grounded from the data. It is not possible to preconceive a null hypothesis in qualitative research. They are purely the domain of certain approaches in quantitative research. Qualitative research uses 'questions' instead. It is not statistically appropriate to test the narrative data that emerges from qualitative data collection. Grounded theory, a qualitative research method, relies on insight generated from the data. Unlike traditional research that begins from a preconceived framework of logically deduced hypotheses, grounded theory begins inductively by gathering data and posing hypotheses during analysis that can be confirmed or disconfirmed during subsequent data collection. Grounded theory is used to generate a theory about a research topic through the systematic and simultaneous collection and analysis of data.

The present qualitative study utilised grounded theory methods (Glaser & Strauss, 1967; (Strauss & Corbin, 1998). One-to-one interviews were conducted with a purposive sample of

18 patients post discharge across the West Midlands region following diagnosis of heart failure. Two interviews per heart failure patient in phases one and two were transcribed verbatim in a preferred language and location of the heart failure patient's choice 12 weeks apart (phase 1 and phase 2) and analysed utilising constant comparative techniques. Furthermore, nine family caregivers were also interviewed (phase 3) in addition to carrying out focus group discussions (phase 4) with a multi-disciplinary team of healthcare professionals (Barbour & Kizinger, 1999; Waterton & Wynne, 1999; Cohen & Manion, 1994).

1.5 STRUCTURE OF THE THESIS

The account of the research has been provided in nine chapters; the structure of the thesis has been presented with the first two chapters introducing the study. In Chapter one, the introduction, justification, aims and significance of the study were presented. Chapter two contained a review of the literature in relation to coronary heart disease and heart failure and subsequent rehabilitation. Chapter three addressed the methodological issues and methods used in the study. Chapter four, five and six presented the findings of the study and described the major research outcomes. These findings established a focus on how the patients' perspectives of their understanding and experiences of managing their condition were constructed. Chapter seven explored the significance of the findings in relation to the literature on heart failure and discussed the implications for improving services. In chapter eight the contribution to knowledge, key findings including developed theory, discussion of a conceptual framework and the implications for practice were discussed. Furthermore, the study's strengths and limitations have been explored in addition to providing recommendations for future research. Finally, chapter 9 offers researcher commentary which at length describes the researchers' journey of undertaking a PhD.

1.6 OVERVIEW OF THESIS CHAPTERS

Chapter one had its profile embedded in identifying and providing an introduction and justification of the study. Chapter two reviewed the gaps in the existing literature on coronary heart disease and more specifically heart failure with Pakistani patients and their family caregivers supporting a need for this study.

Chapter three explored a qualitative approach to the study which draws on the broad principles of grounded theory. The first two phases of the study involved a series of in-depth interviews with a sample of heart failure patients; the third phases included interviews with family caregivers and lastly phase four included focus group discussions with a team of healthcare professionals. The rationale for employing grounded theory, methodological considerations, the specific aims of the study and the methods used have been discussed in addition to the detail of the constructive paradigm and its application in context. Methods of data collection and analysis, including ethical considerations, and strategies used to maintain rigour and quality of the research are discussed in relevant sections of the study. The analyses of the findings from the interviews with heart failure patients and their family caregivers have been discussed in chapters four, five, six. These findings established a focus on how the patients' perspectives of their understanding and experiences of managing their condition were constructed. Chapter seven explored the significance of the findings and how these related to the literature. Attention to new knowledge was also derived from the study. In chapter eight the contribution to knowledge, key findings including developed theory, discussion of a conceptual framework and the implications for practice were discussed. Furthermore, the study's strengths and limitations have been explored in addition to providing recommendations for future research. Finally, chapter 9 offers researcher commentary which at length describes the researchers' journey of undertaking a PhD.

1.7 CONCLUSION

In this chapter I have provided a brief introduction of the study and discussed the layout of the thesis. The proposed research will add to the existing body of knowledge on heart failure with a focus on the Pakistani heart failure population and their family caregivers incorporating the cultural, social and psychological threads that have a significant impact on the incidence of heart failure in the community. In the next chapter, I will discuss the needs of heart failure patients and the role cardiac rehabilitation plays in the management of such a chronic illness.

2 CHAPTER TWO: LITERATURE REVIEW

This review will start by addressing a critical discussion of the literature relating to heart disease and chronic heart failure (CHF). The review will then move on to critically engage with major themes related to HF so as to understand the nature of HF from a cross-cultural and cross-gender perspective relating to health beliefs, health behaviours and health models. It must be stressed however, that, despite a large number of health models, it has been shown that the efficacy in behaviour change within ethnic minority groups is not always effective.

An overview of the main themes within HF literature, including causes, symptoms, treatments and diagnosis HF will be discussed. Furthermore, the main factors influencing the risk of HF will be discussed in order to understand why evidence suggests that the South Asian (SA) population are more at risk of developing this disease. Finally, a focus on cultural differences and cultural barriers will be explored which prevent SA from accessing the same service provisions and level of care as the majority White population which leads to higher instances of readmission. It is important to note that although the thesis is exclusive to the Pakistani population, much research covers SA more generally without making distinctions between different populations within it.

2.1 LITERATURE SEARCH STRATEGY

A literature review is important to all steps of the research process. The review of literature provides a knowledge base for research to develop and more specifically excludes duplication and repetitiveness (Barnes, 2006; Webster & Watson, 2002; Hart, 2018; McCallin &Antoinette, 2003). A literature review for this study allowed the opportunity to explore existing qualitative evidence on self-management experiences of all patients with heart disease more generally, including those with CHF and HF. A pragmatic and cautious approach was undertaken towards the literature (Strauss & Corbin, 1998). It was not possible to go into my study blind as I had undertaken a volunteer position at a cardiac rehabilitation trust within the West Midlands prior to my study; in addition, I had also undertaken an employment research post focussing on coronary heart disease which meant I had both experience and knowledge. Moreover, I had read literature to develop my proposal and ethics application for both the NHS and university.

Furthermore, guidance from supervisors was to read literature more broadly around various aspects of my study in addition to selected literature offered by the supervisory team. Thus, a balanced approach of neither full immersion nor lack of contact was employed. I chose to explore the literature prior to data collection for those reasons despite it being a point of contention in GT methodology where the researcher is encouraged to ignore the existing literature before entering the research field (Glaser, 1978a; Glaser, 1978b).

The literature review undertaken was not a systematic review. I sought to be thorough through the use of robust search strategies and recommendations of key papers as referred by fellow academic colleagues, supervisory team and NHS health professionals I worked alongside. Having undertaken three separate literature reviews, I hoped to attain a wide range and comprehensive overview of the key issues surrounding HF management within minority populations, and more specifically the Pakistani HF population.

The initial literature review question loosely set out to explore existing qualitative evidence on self-management experiences of all patients with CHD more generally, including those with CHF. HF Insight into the process of cardiac rehabilitation, health provision and guidelines as set by health professionals, risk factors, and ethnic minority groups underpinned the search process of questions that would open the pathways of unanswered knowledge. This evidence-based knowledge would allude to gaps in knowledge rejecting the theoretical sensitisation brought into the research and prevent prior knowledge distorting the researcher's perceptions of the data, integrating a fruitful and enriching theory emergence.

A literature search was conducted in July 2010 and repeated at regular intervals (2011, 2013, 2015) to further home in on cardiac rehabilitation needs and experiences of Pakistani HF patients and their family caregivers, as this was an iterative process.

The search strategy involved using key words: 'coronary heart disease', 'SAs', 'risk factors', 'qualitative', 'focus groups', 'qualitative studies', 'epidemiology', 'culture', 'lifestyle', 'religion', 'Pakistani', 'health attitudes' and 'health behaviour', 'ethnic minorities', 'HF', 'HF management', 'HF experiences', 'co-morbidities', 'self-management', 'family caregiver role', 'rehabilitation', 'role of women in health', 'management of chronic conditions', 'health service provision and access', 'NYHA classifications', 'educational programmes', 'cardiovascular disease', 'chronic heart disease', 'coronary heart disease', 'perceptions of illness', 'healthcare professionals in healthcare', 'cardiac rehabilitation', 'experiences of chronic illness', 'NICE Guidelines', 'gender in healthcare', 'cardiac rehabilitation and Pakistani', 'HF and Pakistani', 'HF and SAs', 'HF and gender', 'HF and family caregivers'.

The search terms were limited to English-language articles only. The search strategy involved using Boolean operators for combinations of keywords. The search strategy identified articles between 1997-2015 within the following databases: Summon, Web of Science, Assia, Cinahl, Medline, Pubmed, HeartLung, CHD Nursing, PsychInfo and Cardiovascular Nursing. I wanted the inclusion criteria to be as broad as possible. Multiple relevant papers were included at the time of writing. The literature regarding HF management was predominantly, but not exclusively qualitative as the techniques used in qualitative studies were better suited to exploring and understanding experiences than quantitative studies, which collected data from a range of pre-defined answers. However, effective searching for qualitative literature was notoriously difficult (Barbour, 2003). One reason was that many journals that have published qualitative research were not included in main electronic databases (Barbour 2003). Furthermore, electronic databases used a limited range of keywords that varied between databases, and usually only described general topic areas rather than researcher's specific interests (Barbour, 2003). Subsequently, it was possible that some relevant papers were overlooked despite a robust search process.

The inclusion criteria sought to be broad. Any English language articles were included that were predominantly concerned with the experiences of living with HF, HF ethnic minority groups, CHD, related co-morbidities and perspectives of family caregivers. A variety of terms with different, overlapping or interchangeable meanings were included; for example, 'HF', 'HF management', 'HF experiences' and 'chronic HF'. Articles that met the criteria were examined for relevancy by title and abstract, and consequently a total of 219 papers were included at the time of writing. Non-English articles were excluded, as were duplicate articles.

2.2 PAKISTAN

2.2.1 SOUTH ASIANS

The term 'SA' has encompassed people who are heterogeneous in terms of their country of origin (Afghanistan, Bangladesh, Bhutan, India, Nepal, Maldives, Pakistan and Sri Lanka), race, ethnicity, culture, religion, geographical origins, gender, class, caste and creed, occupation and so forth (Fleming & Gillibrand, 2009). People of SA origin have represented one of the world's biggest ethnic groups (Shantsila et al, 2011) and are currently the largest and fastest growing ethnic minority group in the UK (Darr et al, 2008; Moe & Tu, 2010; Shantsila et al, 2011; Sriskantharajah & Kai, 2006). Moreover, a substantial proportion of SAs have been living in different parts of the world, including East Asia, East Africa, Europe and North America; therefore, what questions arise as to what this then means for other populations (Shantsila et al, 2011).

The first wave of mass immigration of SAs to the UK began in the early 1950s. They consisted of people from three main areas: the Punjab province of both Pakistan and India, and Sylhet that is now part of Bangladesh. The Pakistani and Sylheti immigrants were mainly Muslim, whereas the Indian immigrants were largely Sikhs. These immigrants were mostly factory workers, with little or no knowledge of English and were from low socio-economic backgrounds; the education and earning power of this group of immigrants were often low with added communication difficulties. The main concentration of these immigrants was in Manchester, Bradford, West Midlands and London, which is still the case for most SAs now living in the UK (Hanif & Karamat, 2009).

The second wave of SA immigrants was during the mid-1970s due to political issues in East Africa. They were mainly Gujarati Hindus, who were well-educated and had been business people in East Africa. The third wave was immigrants, who were highly skilled, (who came) and had come from South Asia since the 1950s; they were often doctors working in the NHS (Hanif & Karamat, 2009). Although this thesis has referred to SAs as a whole, it has focused only on the Pakistani population.

2.2.2 DEMOGRAPHICAL OVERVIEW OF THE MINORITY ETHNIC POPULATION IN THE UK

Recent estimates of the size of the Black and minority ethnic (BME) population of Britain was derived from the 2011 census, which suggested a third identified as Asian/Asian British (33%, 2.4 million) and 13% (992,000) identified with Black/African/Caribbean people living in Britain who considered being from a minority ethnic group. A broad range of ethnic groups was found with Iraqi and Iranian born residents. For Iraq, most common was Arab (39%), Any Other ethnic group (28%) and Asian (17%). For Iran, most common was Asian/Asian British (38%) and Any Other ethnic group (34%). A high proportion of residents who were Kenyan, Tanzanian and Ugandan born identified as Asian (69%, 68% and 58% respectively). Of the foreign-born population in England and Wales, nearly half identified as Christian (48%) and a fifth identified as Muslim (19%). Around 1 in 7 had No religion (14%).

Best current estimates, for midyear 2011, were that BME groups made up 7.9% (one in twelve) of the UK population – 4.6 million people. When confined to the population of England, the proportion of minority ethnic origin rose to 9.1% (one in eleven), of whom just over half (4.6 of the population) were of SA (Indian, Pakistani, Bangladeshi, and ‘other’) origins. People of Caribbean and African origin (‘Black’) made up 2.3% of the English population: the remainder were of various origins including Chinese, ‘Mixed’ (i.e. dual heritage) backgrounds, and Others (including Arab and other groups which were not separately identified). Around 1%-2% of the population in England were estimated to be of Irish origin. The 2011 Census had shown that England and Wales had become more ethnically diverse, with minority ethnic groups continuing to rise since 1991. The proportion identifying with a White ethnic group had decreased from 94% in 1991, to 86% in 2011. In 2011, 87% of the population (48.6 million people) were born in the UK and 13% of the population (7.5 million people) were born outside the UK.

As a general rule, it was the case that most people of the black and minority ethnic (BME) communities were living in areas of relative deprivation, and that overall, people belonging to these ethnic groups were relatively disadvantaged in social and economic terms. The Pakistani and Bangladeshi communities have shown much lower employment rates and higher unemployment rates (Office for National Statistics, 2011).

The majority of people of BME origin live in the Greater London area or the West Midlands, with smaller numbers in West Yorkshire and Greater Manchester, and other major metropolitan centres such as Liverpool and Cardiff. Relatively few live in rural areas. According to the 2011 Census, 45% (nearly half) of ‘minority ethnic’ populations live in Greater London, where they form 29% of the population overall. Furthermore, 13% of the BME population was resident in the West Midlands region, accounting for around 2% of the population of the North-East and South-West regions, where it may be suggested that services will be least likely to be attuned to their needs. Other major urban areas have shown the proportion of people of minority origin have been roughly comparable with the national average. Certain minorities were even more concentrated in London – 78% of the population who gave their origin as ‘Black African’ lived in London (largely in four boroughs, south of the river Thames) while nearly two thirds of the Caribbean origin population (61%) was also located in London.

Some towns or metropolitan boroughs have become known for local concentrations of people from particular ethnic origins. Relatively large numbers of people from Somali backgrounds live in Liverpool, Sheffield, Cardiff, Birmingham and Leicester. More than half the UK population of Bangladeshi origin live in the ‘East End’ of London, mostly in Tower Hamlets. Similarly, Leicester has become known as a town whose economy has grown since the resettlement of Asian people (many of them, Gujarati speakers) who sought asylum from events in east Africa in the 1970s, and the 2011 census has shown that over a quarter of the population is of ‘Asian Indian’ origin.

Birmingham has large populations of Punjabi, Pakistani (and/or Kashmiri) background, as well as a significant population of Caribbean background. The largest numbers of people of West African background were found in South East London. The majority of people of SA origin in the northern towns of Yorkshire and Lancashire were of Pakistani origin, many deriving from the Mirpur area of Kashmir. Current estimates were that there were more than three million speakers of other languages in England and Wales, but probably only one per cent (300,000) of these had no ability in English. The remainder had a very basic understanding of spoken English (Office for National Statistics, 2011).

Levels of skills in English varied, both between people speaking different languages, and also from town to town between people who appeared to be of similar ethnic origin. On current data, (Asian) minority ethnic women especially in Muslim cultural groups were the least likely to speak or read English; they may also not have been literate in their ‘mother tongue’. Some languages, notably the Sylheti dialect of Bangladesh, do not have an agreed written form. Those who could speak Punjabi or a dialect variety of it, including Kashmiri forms such as Pahari and Mirpuri, may not have been able to read it, or only to read in either Urdu or the ‘Gurmukhi’ (Devanagri) script.

The 2001 Census was the first to ask a question about religion in England, Wales and Scotland. Figures suggested that 37.3 million people in England and Wales stated that their religion was Christian; (with) 3.1% of the population in England were Muslims, and a further 1.1% Hindu, 0.7% Sikh, 0.5% Jewish and 0.3% Buddhist. The number(s) of Muslims in Britain has been estimated variously at 1 million and (two) 2 million, compared to the Census estimate of 1.54 million; many of these, however, may not have been members of minority ethnic groups. On the other hand, less than (five per cent) 5% of ‘Asian’ groups surveyed said they had ‘no religion’, compared to about a third of the white population (Modood et al, 1997). About half of the ‘Indian’ group interviewed in a national survey said they were Sikhs, while a further third were Hindu (Modood et al, 1997). Many Vietnamese were members of the Roman Catholic faith, while others were Buddhist (as were many Indians and Chinese, and some Pakistanis). Religion was key to many people from a minority background and may play an important part of their ethnic identity.

2.2.3 BRITISH PAKISTANI POPULATION

British Pakistanis, also known as Pakistani British people or Pakistani Britons were citizens or residents of the United Kingdom whose ancestral roots lie in Pakistan. These included people born in the UK who were of Pakistani descent, and Pakistani-born people who had migrated to the UK. The majority of British Pakistanis originated from the Azad Kashmir and Punjab regions, with a smaller number from other parts of Pakistan including Sindh, Khyber Pakhtunkhwa and Balochistan.

According to the UK Census 2011, the British Pakistani population was the second largest SA minority in the UK and encompassed several generations. The UK had the largest Pakistani community in Europe with over 1.1 million Pakistanis living in the UK (Office for National Statistics, 2011 Census).

A high proportion of the Pakistani communities in the West Midlands and the North originated from Azad Kashmir. Large Azad Kashmiri communities have been found in Birmingham, Bradford, Oldham, and the surrounding northern towns. Luton and Slough have the largest Kashmiri communities in the south of England, while a large proportion of Punjabis also resided in the South (Lupton & Power, 2004). There was also a small Pakistani Pashtun population in the UK.

Most Pakistanis (over 90%) in the UK are Muslims. The largest proportions of these belonged to the Sunni branch of Islam, with a significant minority belonging to the Shia branch. Other notable sects included Ahmadiyya and Sufism. Mosques, community centres and religious youth organisations played an integral part in British Pakistani social life. Pakistanis account for 38 per cent of all Muslims in England and Wales (Office for National Statistics, 2011 Census).

Most British Pakistanis speak English, and those who were born in the UK would consider British English to be their first language. Pakistani English was spoken by first-generation and recent immigrants. Urdu, the national language of Pakistan, was understood and spoken by many British Pakistanis at a native level, and was the fourth most commonly spoken language in the UK. As the majority of Pakistanis in Britain were from Azad Kashmir and Punjab, some common languages spoken amongst Pakistanis in Britain were Punjabi and Kashmiri, in addition to Potohari, Mirpuri and Hindko, which are closely related dialects of Punjabi. Other Punjabi dialects were also spoken in Britain, making Punjabi the third most commonly spoken language. Other significant Pakistani languages spoken include Pashto, Saraiki, Sindhi, Balochi and a minority of others.

The number of ethnic minorities has grown in all local authorities. However, as this number continued to rise, the concentration of ethnic minorities in certain inner urban areas increased whilst the White population of these areas decreased resulting in ethnic minorities becoming more isolated and residing in confined known areas (Sabater & Simpson, 2009).

Immigration to the UK from the region which is now Pakistan began in small numbers in the mid-nineteenth century. Historically, Pakistan came under the British Raj and people from those regions served as soldiers in the British Indian Army. Following the Second World War, the break-up of the British Empire and the independence of Pakistan and India led to Pakistani immigration to the UK in the 1950s and 1960s when Pakistan was a member of the Commonwealth (Hanif & Karamat, 2009).

Upon migration to the UK, Pakistani immigrants helped to resolve labour shortages in the steel and textile industries. Medical professionals from Pakistan were recruited and almost all worked for the National Health Service. Additionally, professionals from academic and engineering backgrounds were invited to work, advancing the contribution towards greater economic opportunities.

The British Pakistani population grew from 10,000 in 1951 to over 1.1 million in 2011 (Office for National Statistics, 2013) and the vast majority of these lived in England, with a sizable number in Scotland and smaller numbers in Wales and Northern Ireland. Up to 250,000 Pakistanis come to the UK each year, for work, to visit or for other purposes**.** Likewise, up to 270,000 British citizens travel to Pakistan each year, mainly to visit family.

British Pakistanis since their settlement to the UK have had diverse contributions and influence on British society, politics, culture, economy and sport. Whilst social issues included high relative poverty rates among the community according to the 2001 Census, significant progress has been made in recent years, with the 2011 Census showing British Pakistanis as having amongst the highest levels of home ownership in Britain. A large number of British Pakistanis have traditionally been self-employed, with a significant number working in the transport industry or in family-run businesses of the retail sector (Kenway & Palmer, 2007).

Most early Pakistani settlers (then part of the British India Empire) and their families moved from port towns to the Midlands as Britain declared war on Germany in 1939. These Pakistanis served in the war alongside the British Army during the First and Second World Wars, particularly the latter. Many of these Kashmiris, Punjabis and Sindhis worked in the munition factories of Birmingham and subsequently stayed in the region after the war due to increased job opportunities. These settlers were later joined by the arrival of their families to Britain as secondary migrants following the independence of Pakistan (Hanif & Karamat, 2009).

However, post de-industrialisation in the 1970s, many British Pakistanis became unemployed in the UK hence resorting to self-employment.

In the 2011 UK Census, 1,174,983 residents classified themselves as ethnically Pakistani regardless of their birthplace (Office for National Statistics, 2013). The equivalent figure in the 2001 UK Census was 747,285 (Office for National Statistics, 2004). It was recognised that 55% of those Pakistanis lived in the UK. According to estimates by the Office for National Statistics, the number of people born in Pakistan living in the UK in 2013 was 502,000 (Office for National Statistics, 2014). The Ministry of Overseas Pakistanis (Pakistan government) estimated that 1.26 million Pakistanis eligible for dual nationality lived in the UK, constituting well over half of the total number of Pakistanis in Europe (Cheema, 2012).

Pakistan has celebrated its Independence Day on 14th August each year as have large Pakistani-populated areas of various UK cities. Pakistani Muslims also observe the month of Ramadan and mark the Islamic festivals of Eid ul Adha and Eid ul Fitr. Ramadan is a religious obligation to each Muslim as part of their Islamic faith. However, in certain cases it was permissible to be exempt from fasting, these restrictions were usually applied on the basis of health.

Pakistani cuisine was extremely popular in the UK and has successfully nurtured a profitable business in the food industry with many Pakistanis owning thriving takeaways and restaurants. The Pakistani food industry was highly representable of its origins, reflecting the stringent ethnic backgrounds of the Pakistanis living in the UK. According to the Food Standards Agency, the SA food industry in the UK was worth £3.2 billion, accounting for two-thirds of all eating out, and serving about 2.5 million British customers every week (The Guardian Group, 2010).

Pakistani families place much emphasis upon faith, cultural traditions and family values. A majority of Pakistanis identified themselves with Britain, feeling a sense of belonging with the country with progressive immersion into the country. However, the cultural values of Pakistanis have clashed with British ones; Western values associated with ‘freedom’ have caused contentions. Nevertheless, a transition from family businesses consisting of takeaways, restaurants and taxi firms to taking admissions in higher education within the academic sector has made notable progress in the UK. The younger generation have exceeded in higher education with credentials that showcase abilities of achievement and success.

A large proportion of the earlier generations of the Pakistani community living in the UK were recognised as living in relative deprivation with many in areas of high population and social deprivation (Bahl, 1993). The Pakistani community within the UK experienced barriers in both accessing health care and the care that they received. These barriers were mainly due to culture, ethnicity, language and religion which all reinforce one another (Astin et al, 2008a). This was an area that needed to be examined further and will be looked at in more depth. Much of the Pakistani population were less likely to have the knowledge and understanding of how to access and seek appropriate medical advice and healthcare which could improve their quality of life, health, wellbeing and decrease the risk of morbidity and mortality. People from ethnic minority backgrounds were often educationally and economically disadvantaged, resulting in being less able to gain access to educational materials (Johnson et al, 2006a).

Much evidence has echoed support for CHD, hypertension, multiple myocardial infarctions and diabetes as the leading causes of HF in SAs due to its susceptibility. The literature related to culture, ethnicity, language and religion in relation to HF was limited and often ethnic background was not reported. Thus, the inclusions of the Pakistani community and its needs in the UK have been neglected as a separate entity as it has been paired with SA groups or otherwise. A demand for further research to explore the needs of the Pakistani community specifically was essential if wider understandings of the components amalgamating the Pakistani community in the UK were to be understood and addressed.

2.2.4 ISLAM

Laailaaha illallahu Muhammadur Rasulullah

Translation: There is none worthy of worship besides Allah and Muhammed [PBUH] is the messenger of Allah.

This pledge and declaration is the key to the door that is Islam and the foundation of one's faith and belief. The acceptance and sincere recitation of this statement provides the believer the title of being a Muslim and thereby earns them salvation and safety from hell attaining an entrance into Jannah (paradise).

Islam is a way of life which was brought into this world by Allah, via the last of his messengers, Prophet Mohammed [PBUH]. Islam is the world's second largest religion and the fastest growing major religion with over 1.7 billion followers or 23% of the global population, known as Muslims. The teachings of Islam teach that Allah (God) is most merciful, all-powerful, unique and that none except Allah is worthy of worship. The emphasis is that Allah guided mankind through revealed scriptures, natural signs, and a line of prophets sealed by the last messenger, Prophet Muhammad [PBUH]. The primary scriptures of Islam is the Quran, viewed by Muslims as the verbatim word of Allah, and the teachings (called the Sunnah, composed of accounts known as hadith) of Muhammed [PBUH].

Most Muslims are from one of two denominations, Sunni or Shia, with the minority of the latter (12%-20%). A majority of Muslims reside in Indonesia, South Asia and the Middle East-North Africa (MENA). A sizeable Muslim community can also be found in Europe, China, Russia and America (Sahib et al, 2013)

There are five basic religious acts in Islam, collectively known as 'The Pillars of Islam' (arkan al-Islam; also arkan ad-din, 'pillars of religion'), which are considered obligatory for all believers. The Quran presents them as a framework for worship and a sign of commitment to the faith. These are:

1. The creed (Shahadah)

2. The five daily prayers (Salat)
3. Charity (Zakah)
4. Fasting (Ramadan)
5. Pilgrimage (Hajj, Mecca)

The first duty of Islam, after one has believed in the Oneness of Allah and the prophet-hood of Prophet Muhammed [PBUH], is Salaah (prayer). Five daily prayers offered with punctuality in congregation at the mosque.

Among the fundamental teachings of Islam, Zakaat (charity) is the third most important after declaration of faith and prayer. This is known as the third pillar of Islam. Zakaat essentially means that a Muslim who is in possession of a certain amount of wealth in excess to his needs is required to spend one-fortieth (2.5%) of it at the end of every (lunar) year on the poor and most needy Muslims as ordered by Allah and Prophet Muhammed [PBUH].

The fourth pillar, Saum (fasting) is compulsory for Muslims to adhere to during the holy month of Ramadan. Fasting promotes piety and righteousness in a person and has been prescribed obligatory as it disciplines the soul from worldly pleasures, desires and sinful deeds. Together with abstaining from food and drink, a distance between slandering, quarrelling and engaging in lying and backbiting is prohibited in addition to sexual intercourse. When a person fasts, he rises above the existence of the animals and thrives to develop angelic qualities.

Hajj (pilgrimage) is the fifth pillar of Islam and it is a duty of a Muslim to find a way to the Kabah, the house of Allah in Makkah (Saudi Arabia). Hajj has been declared obligatory, it has been made clear however, it is only applicable to those who possess the means to carry it out. Almighty Allah advocates Hajj in an attempt for mankind to attain forgiveness and mercy, for sins to be forgiven.

Etiquette, good manners and respecting the rights of others, form an important part of Islamic teachings. Many practices fall in the category of adab, or Islamic etiquette. This includes greeting others with ‘Assalamu’alaiykum’ (‘peace be unto you’), saying Bismillah (‘in the name of God’) before eating meals and using only the right hand for drinking and eating. Islamic hygiene practices mainly fall into the category of personal cleanliness and health. The practice of circumcision and Islamic burial rituals, Salat al-Janazah (funeral prayer) are key to the structures of symbolic Islam (Sahib et al, 2013). Muslims are restricted in their diet. Prohibited foods include pork products and alcohol. All meat must come from an herbivorous animal slaughtered in the name of God by a Muslim, Jew or Christian. Food permissible for Muslims is known as halal food.

The implications therefore of Islamic teachings for the experiences of HF and the process of rehabilitation are imperative; health is foremost in Islam, with the wellbeing of a Muslim a priority. Thus, prioritising the self (patient and family caregiver) and caring for the needs of the body are essential. The negotiation of a balanced approach to a healthy lifestyle holistically is an advocate of Islamic principles and its teachings.

2.2.5 ETHNICITY AND CULTURE

The term ethnicity has been defined as a collective group within a larger population having a real or putative common ancestry, common history and knowledge, shared territory or nationality and a cultural focus upon one or more symbolic elements which define the group's identity such as collective name, common language, sense of belonging and community and kinship, behavioural norms, values and customs (Dein, 2006; Banerjee et al, 2010a; Gerrish, 2000). The term ethnicity was fluid and can vary in terms of place or time. This caused a problem when trying to assign people to specific ethnic categories (Dein, 2006). Ethnicity comes from the Greek word 'ethnos', meaning a nation, people or tribe.

Race has been defined as a larger group of people with common ancestry, for both biological reasons and the fact that the social concept of race emphasised lineage, because it impacts on both identity and cultural and political heritage. These were retained across many generations. The characteristics traditionally underling racial groups, (e.g. skin colour) were largely inherited mainly through the ancestral line.

Ethnicity and race in health research demanded insight into improved health status by understanding diseases better which in turn aimed to tackle inequalities and promote health service delivery.

Culture has intertwined with ethnicity where culture is inherited and the way in which people perceive the world and a way of life (Banerjee et al, 2010). It can be seen as a subjective and fluid concept whereby an individual interprets and creates his own version of culture (Csordas, 1994, 2002; Williams & Barlow, 1998 cited in Fleming & Gillibrand, 2009). Although they may be influenced by those around them, essentially the individual was not a product of an overriding culture but he constructed his own idea of culture (ibid). Culture involves a multitude of factors that give a sense of ethnic identity and belonging and affect one's lifestyle and susceptibility to disease including HF. Pakistanis have unique factors which enable them to have a sense of identity and kinship (Hanif & Karamat, 2009) and can be seen as an ethnic group who construct and represent their culture through their practices in everyday life. Pakistan's Independence Day is celebrated on August 14th each year and Pakistani Muslims also observe the month of Ramadan and mark the Islamic festivals of Eid ul Adha and Eid ul Fitr. They also represent and renew historical cultural practices, which can affect their decision to attend CR and adhere to the medical advice they have been offered (Banerjee et al, 2010b). Therefore, cultural understanding is paramount as interactions between a healthcare provider and a Pakistani patient can be classed as a cross-cultural transaction. The Pakistani patient will exhibit his own attitudes, beliefs and knowledge, which are embedded within his culture. These attributes will ultimately affect and reinforce his health practices and may have an effect on the information shared with the healthcare provider and the level of care which he receives. Therefore, cultural knowledge and sensitivity were key to improving the quality of care the Pakistani patient receives (Banerjee et al, 2010a) as conflict can arise between Western concepts of healthcare and the needs of Pakistanis who live in the UK and practise Pakistani cultural traditions (Cortis, 2000a).

With an international growth of migration and increasing socio-cultural diversity in their populations, most European countries were faced with the need to view their healthcare services. It was essential that healthcare staff were equipped with the knowledge and resources to provide personalised culturally appropriate adapted care and health promotion for all inclusive of ethnic differences (Culley et al, 2007).

Little attention was drawn to both men and women of ethnic minority in healthcare needs and experiences of infertility in Western societies received less than optimal care. Barriers to communication were more than language specific and evoked cultural differences (Netto et al, 2010). If cultural diversity was to be recognized, it was often used against ethnic minority populations (Karlsen et al, 2007). Evidence suggested families of ethnic minority were often associated with their ‘deviant’ cultural practices and lifestyles (Ahmad & Bradby, 2007) leading to stereotypes and inappropriate myths that essentialised static entities (Atkin & Chattoo, 2007). Delivery of healthcare must account for migration, culture and ethnicity as well as socio-demographic factors such as education, social status, age and gender when addressing health inequalities. Untangling language and cultural differences to understand the barriers affecting ethnic minority groups were essential to accessing equality within reproductive technology services (Johnson & Borde, 2009). The inclusion and engagement of ethnic minority groups was essential as it unfolds insights into culturally specific practices that are necessary to health promotion.

It was important to remember that cultural divisions within society were not only due to the country of origin, but also included economic status, employment, education and social class and, therefore, healthcare providers must take these into account and put aside any differences to ensure adequate treatment is delivered. The failing of this can lead to cultural segregation whereby a group is labelled as different due to their culture or ethnicity (Vissandjee et al, 2007 cited in Fleming & Gillibrand, 2009). This was especially true for British Pakistanis who are often considered to be homogenous with other SA groups. This can often lead to stereotyping and blaming in regard to their health as SA people were seen as a uniform group whose culture and practices lead to detrimental self-care and health (ibid).

The relationship between culture and religion has been strong, and has often been inextricably linked (Henley, 1979 cited in Bahl, 1993). Islam has been the focal point of the lifestyle of the majority of people of Pakistani origin and governs the practices of its believers and followers (Wilkinson, 2001). Islamic attitudes, behaviours, customs, norms and values were derived from the holy book, the Quran. Western society often found it difficult to differentiate between behaviour and norms which originate from religious beliefs and cultural behaviour which have developed over time. Practising Muslims will follow religious values and codes irrespective of place of residence or origin (Bahl, 1993). Western society often perceived this as typically ‘Pakistani’ behaviour due to the origins of the person. Healthcare providers must place equal consideration and respect on the immigrant population as well as the indigenous population. This being said, Pakistani cultural issues and behaviour were still misunderstood, and this can cause difficulties in healthcare settings, which can arise from prejudice and ignorance (Bahl, 1993). This may be resolved by open discussion between the healthcare practitioner and the patient, which can often prevent frustration and anger.

In relation to HF, Pakistani Muslim patients often have a more fatalistic attitude towards their diagnosis than their White counterparts. There has often been a view that it is ‘God’s will’ and these thoughts often affected their reluctance to take part in CR and follow medical advice (Galdas et al, 2012). However, although many HF patients believed that they did not have much control over their illness, many were still willing to make changes to their lifestyle to improve their health and well-being. This was often suggested as an indicator from God that they have not looked after themselves properly (ibid).

2.3 CORONARY HEART DISEASE

Coronary Heart Disease (CHD) has been the largest single cause of death in the UK and worldwide. In the UK, it accounted for 73,000 deaths each year and approximately, 1 in 7 men and 1 in 10 women die from CHD (British Heart Foundation, 2015). In the UK, there were an estimated 2.3 million people living with CHD and approximately 2 million people affected by angina (the most common symptom of CHD) (NHS, 2016) as well as acute myocardial infarction (MI) and HF. Generally, CHD affected more men than women, although from the age of 50 years the chances of developing CHD were similar for both genders. People of SA descents residing in the UK represented the largest ethnic minority, had a considerably higher mortality rate and were more likely to have morbidity associated with CHD (Chauhan et al, 2010; Darr et al, 2008; Tod et al, 2001a, Tod et al, 2001b).

Women have often been thought to be at lower risk compared to men in terms of heart disease. However, as women get older and their levels of oestrogen drop, they are more likely to develop CHD. It was particularly high amongst SA women. According to Ruston and Clayton (2007), women were at higher risk than men of dying from CHD. In the UK one woman dies every six minutes from heart disease (Visram et al, 2008). CHD caused 12% of all premature deaths in women every year and women had a disproportionate risk of suffering disability after MI and dying within a year after an MI. Women were also less likely to be referred for diagnostic tests and invasive procedures, less likely to be diagnosed with a MI and less likely to be referred for CR. Furthermore, women were less likely to see themselves as vulnerable and less likely to respond to heath messages relating to CHD. This was also coupled with the fact the women were less likely to access and seek medical help after a MI than men (Ruston and Clayton, 2007). The optimum time for this treatment was within an hour of the onset of symptoms, although the earlier treatment was administered the better as this would reduce mortality and morbidity. The benefit of receiving treatment after 12 hours of an MI was severely limited. Recognising these symptoms and calling for medical assistance can be an issue for some patients and can influence whether they received adequate care. However, a lack of understanding surrounding CHD often meant that patients did not have sufficient knowledge and cannot accurately assess their symptoms (Ruston and Clayton, 2007).

The total number of patients suffering from HF was estimated to be between 800,000 (National Heart Failure Audit, 2013) and 900,000 (NHS, 2015; NICE, 2010) in the UK and nearly 6.5 million in Europe (Luttik et al, 2007a; Grant and Garland, 2009). HF affected people of all ages but it was particularly prevalent among people aged over 75 years where there was a sharp increase in the number of people affected. Among those over 65 years, the prevalence of HF continued to increase; while around 1 in 35 people aged 65-74 years had HF, this figure increased to about 1 in 15 of those aged 75-84 years, and to just over 1 in 7 in those aged 85 years and above (NICE, 2010). It was expected that the total number of people suffering from HF would increase due to an ageing population. In the UK, HF affected around 0.9% of men and 0.7% of women (National Heart Failure Audit, 2013), but this figure increased dramatically to 13.1% of men and 11.9% of women over 75 years. According to the National Heart Failure Audit (2013), a total of 43,894 people were recorded as suffering from HF. The audit represented 60% of all HF discharges or deaths in England and Wales. In England, there were a total of 41,932 admissions, which accounted for 61% of the 68,654 people who were recorded with HF in the Hospital Episode Statistics. In Wales, there were a total of 1,962 admissions, which accounted for 47% of the 4,165 patients recorded with HF in the Patient Episode Database for Wales.

2.3.1 HEART FAILURE

Heart Failure (HF) was defined as a condition caused by the heart failing to pump enough blood around the body at the right pressure. The causes of HF were often due to the heart muscle having become too weak or stiff to maintain normal function. HF can develop quickly or gradually, known as acute HF and chronic HF respectively (Deprest, J., et al 2014). HF can affect either side of the heart although Left Ventricular (LV) HF was the most common type and accounted for 60% of patients. Right Ventricular (RV) HF was less common and was usually caused by LV systolic dysfunction, as the heart cannot pump enough blood to the lungs to pick up oxygen (Leslie & Buckley, 2010). HF may cause fluid to build up and retain in the feet, ankles, legs, liver, abdomen and the veins in the neck and may also result in shortness of breath or fatigue.

HF was a common chronic disease that was increasing in prevalence (Luttik et al, 2007a). It can lead to disability and death (Rogers et al, 1997) and affected many people across the world. It was one of the largest medical problems of our time and was the only major cardiovascular disease (CVD) with increasing incidence and prevalence (ibid; Jaarsma et al, 2008). Despite the advances in medical treatment, morbidity and mortality rates remained high. HF was costly, disabling and deadly, despite being treatable, and was an increasing cause of cardiovascular morbidity and mortality within the Western world.

It was expected that the number of people with HF would increase with the growth of the ageing population (Annema et al, 2009). HF affected as many as 10% of the population aged over 75 years and often had a poor prognosis, with a survival rate worse than that of breast or prostate cancer. The ageing population also meant that HF was likely to increase, putting pressure on the resources required to manage it. Paradoxically, although improvement in the treatment of hypertension and MI was likely to delay the onset of HF, it was also likely to increase its incidence and prevalence further (Cleland et al, 2002). The illness was characterised by debilitating physical symptoms and frequent hospitalisations. As a result, HF patients faced many challenges in dealing with and managing the condition and its treatment (Luttik et al, 2007a).

HF is unlikely to be cured but can be managed with careful monitoring. Adhering to medication and managing lifestyle risk factors can improve quality of life leading to prolonged life (Coronel et al, 2001).

2.3.1.1 CHRONIC HEART FAILURE (CHF)

It was estimated around 30% of global deaths were a result of CVD with CHF a major cause of these deaths. The prevalence of CHF in people over 45 years of age was around 3% to 5% of the worldwide population. The majority of people with CHF were female due to their longer life expectancy and it was mainly older people who suffered from CHF with the likelihood of having CHF tripling over the 75+ age bracket (Jeon et al, 2010). CHF was found among 10% of patients of the age of 80 and around 80% of those suffering from CHF were over 75 years of age. As the survival from MI increased, the prevalence and incidences of CHF increased likewise. This was also the result of an ageing population and an increased lifespan in developed countries. In Europe around 5% of medical admissions were related to CHF and it had a major impact on people’s everyday lives regardless of age and gender (Falk et al, 2007a).

A UK study based in an inner-city hospital had 348 admissions for acute CHF with a multi-ethnic population, 76% were Caucasian, 16% were Indo-Asian and 8% Afro-Caribbean (Lip et al, 1997). The non-White patients in the study were significantly younger than the White patients suggesting an earlier onset of the disease. A re-analysis of this study taking into account population data suggested that the relative risk of CHF among patients aged 60-79 years was 3.1 (95%) confidence interval (CI) (1.9 to 4.9) for Afro-Caribbean and 5.2 (95% CI 3.7 to 7.4) for Indo-Asians, suggesting that CHF may have been a major problem among non-Caucasian populations in the UK (Lip et al, 1997; Chaturvedi et al, 2003). A greater understanding of knowledge and disease perceptions among non-White populations may improve the approach to management of CHF within these groups. The views of peers such as family and friends, societal pressures and patient’s own cultural background also affect compliance. Indeed, ethnicity was an important factor especially if there were language difficulties.

Epidemiological and therapeutic trials have involved almost exclusively White populations and evidence from these trials cannot necessarily be assumed to relate to other ethnicities (Sosin et al, 2004a; Sosin et al, 2004b). Data from North America suggested that Black patients when compared to White patients have a similar mortality rate but greater functional decline after hospitalisation for CHF which cannot be explained by clinical, socio-economical, access to care or quality of care differences (Vaccarino et al, 2002).

Symptoms of CHF included fatigue and breathlessness, lack of energy, thirst, frequent urination and loss of appetite (Hägglund et al, 2008). This was also coupled with psychological symptoms such as anxiety, depression, feelings of irritability and social isolation (Falk et al, 2007a); Barnes et al, 2006; Jeon et al, 2010; Nordgren, 2009; Burgess and Whitfield, 2009). CHF was often described as a syndrome rather than a disease with a symptomatic and progressive deteriorating disease trajectory (Yu et al, 2008). Although there have been advances in the treatment of CHF and new pharmacological methods to manage it, the prognosis for CHF was not good. Often patients with CHF died of a sudden cardiac event yet the unstable nature of the syndrome made it unpredictable and meant that patients had often required multiple re-admissions to hospital (Davis et al; 2006).

CHF has been poorly managed and treated in the past; however, recent improvements in pharmacology and advice given on lifestyle changes have improved the prognosis for CHF. Many patients with CHF did not understand the condition properly and did not know how to implement CHF self-care. Often care for CHF was focused on alleviating physical symptoms (Reid et al, 2005; Eldh et al, 2004) and did not take a holistic approach to CHF management (Nordgren et al, 2009). Management of CHF had often focused on patients who complied with the treatment options. There were often many issues with patients' non-compliance, and this could have been seen to be a result of lack of knowledge of the disease and the consequences of their condition. Furthermore, patients with CHF did not always understand the link between their chronic condition and the acute periods of deteriorating health (Mårtensson et al, 2003).

Compliance with medical treatment was likely to be improved if the patient had knowledge and understanding about their condition, the medication available and its side effects (McCormack et al, 1997). The views of peers also influence the compliance of a patient. Patients with chronic cardiac disease condition often had very limited knowledge about the disease and the consequences and need for long term treatment (Lip et al, 2002).

Mårtensson et al (2003) described patients with CHF having a strong desire to live life as normal despite feelings of fear and diminished strength. It was shown that some patients made these choices independently, whereas others that had family strongly involved in decisions with less autonomy over their care. Instances, where household duties were allocated according to the patient's manageability in fact empowered mind-sets as opposed to it being perceived as burdensome. Mårtensson's (2003) study revealed that women with CHF often felt like they were a burden, this was less likely the case for men with the disease. Domestic duties, which had once been routine were now exhausting and tiring. The reaction and perception of life with CHF was thought to be dependent on personal attitudes and characteristics. This was further illustrated in the Boyd et al (2004) study that suggested when a patient's strength was decreasing; home care could be considered as an option for strengthening. However, the Ekman et al (1999) study suggested that patients did not accept help easily as it threatened their independence. Therefore, it is hoped nurses give patients opportunities to share their ideas with others as this may have a positive effect on other CHF patients thus improving their situation. Memories were also seen to be of great importance in daily life as the opportunity to reflect on enjoyable experiences can ease the current burden of life. Furthermore, thoughts of death exist which can affect the zest for life. It appeared that when there was a threat of death there was a strong consciousness to adhere to the prescribed recommendations. It was therefore important that nurses and medical staff paid attention to any indicators given by the patients and were able to give adequate support to the patients and their relatives.

In summary, there were varying definitions of CHF, but there was strong evidence to suggest that CHF affected a significant proportion of HF patients, mostly older people over 65 years. It was possible that ethnicity was a contributing factor to the risk of CHF, but there was little evidence to support this and the evidence that did exist was based on data from White patients. CHF can also have detrimental effects for the patient's social and financial situation, often leading to mental health problems. Many of the issues highlighted from the discussion on CHF were also true for HF in general, to which the discussion now turns.

2.3.1.2 CAUSES OF HEART FAILURE

There were several aetiologies of HF, as well as several psychological and social factors (Fox et al, 2001; Hamner & Ellison, 2005). The psychosocial factors related to lifestyle choices, which result in clinical aetiologies. Some of these aetiologies were responsible for the onset of HF. There existed variation in the literature in relation to the number of aetiologies that can be assigned to HF. It was generally agreed that the following constitute potential aetiologies: heart attacks (MI) which damages the heart muscle leaving scar tissue preventing the heart muscle to work as efficiently as it once did, coronary artery disease (CAD), hypertension (sustained high blood pressure which demands the heart to work harder). The heart muscles become thicker and enlarged and so cannot pump as efficiently, atrial fibrillation, valvular disease (the valves in the heart may not be working properly. Blood does not move through the heart in the right direction and builds up in the heart and lungs. The heart gets bigger but does not pump as efficiently), alcohol, cardiomyopathies and congenital heart disease (this can be caused by an infection of the heart, alcohol excess, or passed on in families). It can also occur without any known causes (See Appendices 11.22 for diagram of HF heart vs. normal heart). It has also been claimed that diabetes can contribute to the onset of HF

(Vaccaro & Huffman, 2012a; Vaccaro & Huffman; 2012b). Chronic obstructive pulmonary disease (COPD) and Cor Pulmonale were also known to cause HF, here fluid will be retained within the body, resulting in swollen ankles, in people with COPD it can be a sign of cor pulmonale – a combination of high blood pressure in the lungs and right sided HF. In COPD many of the tiny blood vessels in the lungs were destroyed, resulting in lower levels of oxygen in the blood stream increasing the blood pressure in the right side of the heart. The heart had to work harder to force enough blood through fewer, constricted blood vessels. As a result of this effort, the right ventricle becomes enlarged, the walls of the heart thicken, and it cannot pump as efficiently. The task of assigning aetiology in order to identify the cause of HF depended on several circumstantial issues. Perhaps the most important of these was the presence of historical evidence (Fox et al, 2001).

The specific aetiologies, such as CAD or hypertension, can be a result of lifestyle choices, which can be broadly categorised into two main contributing factors: nutritional factors and social factors. Nutritional factors included maintaining a poor diet and eating certain types of food (Chauhan et al, 2010b). Social factors included low income, depression, marital status, smoking and a poor exercise regime (Hamner & Ellision, 2005). Both nutritional and social factors created physical problems, such as: high blood pressure and high cholesterol. These physical problems then developed into one or several aetiologies of HF. However, the largest single cause of HF was coronary heart disease (CHD) and so this issue has warranted further discussion.

2.3.1.3 SYMPTOMS OF HEART FAILURE

The New York Heart Association (NYHA) classified HF according to four different levels of impairment. Class 1 impairment involved no symptom limitation with ordinary physical activity. Class 2 impairment was when ordinary physical activity was somewhat limited by dyspnea, such as long-distance walking and climbing two flights of stairs. Class 3 impairment was when exercise was limited by dyspnea with moderate workload, such as short-distance walking and climbing one flight of stairs. Class 4 impairment involved dyspnea at rest or with very little exertion (NYHA).

There was a general consensus among the literature that there was a strong correlation between HF and mental health issues, in particular depression (Siabani et al, 2013; Evangelista et al, 2009). Many HF patients also suffered from depression. Research has shown that there was a clear link between the symptoms of HF having a direct impact on the patient’s quality of life (QoL) (Nordgren et al, 2007a; Nordgren et al, 2007b). As a result of the reduced QoL, patients often developed depression or anxiety. In a study conducted by

Hägglund et al (2008), over 80% of a group of elderly people with HF reported the symptoms of fatigue, shortness of breath, having difficulties walking or climbing stairs and having to rest during the day. These appeared to be some of the more typical symptoms of HF (Ried et al, 2005; Imes et al, 2011) and those that were most likely to impair a patient's QoL. Paradoxically, these symptoms also hindered the patient's recovery as many of the rehabilitation methods for HF patients involved exercise. Due to the difficulties HF patients faced with physical activity, maintaining HF rehabilitation can be challenging. This impairment to QoL constituted one of the main factors influencing the development of mental health issues, namely depression and anxiety (Hägglund et al, 2008; Schnell & Standl, 2006; Falk et al, 2007a; Falk et al, 2007b).

There were also several atypical symptoms of HF recorded, including loss of concentration, poor attention and memory, weight loss, imbalance and feeling pain, weakness and insomnia (See Appendices 11.25). However, the prevalence of these atypical symptoms was unknown. Nevertheless, these symptoms also created challenges for HF patients, as they still had to deal with physical limitations, coping with treatment regimen, lack of knowledge, negative emotions and personal struggles (Riegel & Carlson, 2004).

2.3.1.4 TREATMENT OF HEART FAILURE

The treatment of HF has three main goals: a) prevent the development of HF; b) counteract deleterious effects of cardiac remodelling; and c) reduce the symptoms that the patient suffers. The most important aim was to improve the patient's QoL (Heo et al, 2009b). This was done by providing more information for patients and family caregivers or by consolidating existing social support networks.

In terms of drug treatment, HF patients were prescribed multiple medicines (Mehta & Cowie, 2006). In a study conducted by Fonarow (2004), there was a significant decrease in hospitalisations and health costs and an increase in functional and symptom status among patients involved in a self-management programme. According to Field et al (2006), the majority of HF patients perceived medication in the form of tablets. Patients were divided between those who believed the medication was doing them good and those who did not know if the medication was doing any good but continued to take them because they trusted the medical professional who prescribed them (Reid et al, 2006). Medication management was secondary to self-care and/or behavioural lifestyle changes.

In addition to drug treatment, HF treatment can also involve attention to the psychological sequel of CHD. These treatments can include counselling, relaxation and stress management strategies. It can also include non-medicinal approaches, such as behavioural and lifestyle changes, and smoking cessation. Fiore et al (1990), Burling et al (1984) and Rigotti et al (1994) found that patients were more likely to stop smoking when it was self-motivated rather than in a smoking cessation group, or where it was forced upon them.

Many HF patients had difficulty with maintaining a rehabilitation routine. One of the major problems found was that patients were not familiar with or had not been told about the box system for keeping track of medications (Reid et al, 2006). In the majority of cases, medical professionals had not advised patients about this and so patients relied on family or carers to provide this information. There were very few cases where patients had consciously chosen not to take the medication. The majority of cases where patients had not taken the medication were due to the breaking of their normal daily routine or they had simply forgotten (ibid). As a result, it was important that medical professionals burden the responsibility for educating patients of the importance of taking the medication, the importance of routines, to identify when the routine has been broken and, most importantly, how to create and maintain a system for keeping track of the medication. If medical professionals explained why it was important to take the medication, rather than simply prescribe it and assumed the patient will take it based on trust, then patients were more likely to understand why they have been prescribed the medication, why they have to take it and what the consequences may be if they did not take it. This will reduce the number of patients who think they must take the medication because the medical professional has said so and so the patient must rely on trust. Explanations of prescribed medicines must be delivered as part of information delivery of medicines management.

According to Heo et al (2009b), around 59% of patients were readmitted to hospital within 19 months of being discharged. However, some 50% of these readmissions could have been prevented because 55% had experienced reduced HF symptoms. If there was an increase in symptoms then it was likely due to a reduction in the efficiency of self-care, in particular diet. If patients did not follow the nutritional recommendations made by health professionals, such as minimising or eliminating sodium-rich foods (Sisk et al, 2006), then there was a greater likelihood of readmission to hospital and a greater likelihood of an increase in symptoms. There was a general consensus in the literature that HF patients have a poor understanding of nutrition and the dietary requirements resulting from the condition (Heo et al, 2009a). As a result, it was essential that patients were educated about nutrition and dietary regimes they must follow especially in regard to a low-sodium diet (Sheahan & Fields, 2008). Further attention to the cultural recognition and importance of palette must be entwined as detail to over consumption of favourite foods was reduced (Hebebrand et al, 2014). Based on research by Heo et al (2009a) 40% of patients said that they did not follow a diet that involved minimising sodium intake (ibid). They argued that if HF patients understood the importance of nutrition then it would be possible to improve interventions in order to increase the number of patients following the nutritional requirements. The result of this could be fewer hospital readmissions. A reduction in multiple readmissions may be improved with improved information delivery as opposed to poor self-management, which was steered with poor knowledge.

Self-care referred to self-maintenance involving activities such as self-monitoring (of indicators of fluid volume overload) and self-medication (adherence to medication prescription) and adopting lifestyle behaviours (such as eating a low salt-diet, stopping smoking, limiting alcohol intake and taking regular exercise). Self-management also involved seeking help when decision making and strategies became overwhelming and failed to relieve symptoms (Hebebrand et al, 2014; Riegel et al, 2009; Ditewig et al, 2010; Rozentryt et al, 2010).

Despite advances in HF treatment, hospital discharges have increased linking symptoms to lack of appropriate self-care (Heo et al, 2008; Bennet et al, 1998; Ghali et al, 1988). People have a key role in protecting their own health, choosing appropriate treatments and managing long-term conditions in the hope that such measures override poor knowledge and eradicate misconceptions preventing frequent re-hospitalisations for HF and mortality. Everyday self-care decision-making was therefore critical to disease management, especially within the community setting. Self-management can improve long-term chronic conditions. Equipping service users with the correct tools needed to manage their health elevated and enriched their status. Empowering patients with correct knowledge, information and encouragement played a central role in illness and such recognition with strategic efforts can stretch decisions about informed care, engaging patients in healthy behaviours.

Multiple influences on self-care behaviours have been reported, these included individual patient-related factors such as gender, age, co-morbidity, cognitive and psychological factors as well as organisational issues related to the delivery of healthcare and the extent to which it facilitated a supportive patient-professional relationship (Heo et al, 2008; Riegel et al, 2011); Mårtensson et al, 2003; Riegal et al, 2006; Lee et al, 2005; Buck et al, 2015).

Effective self-care support required a collaborative approach between patients and healthcare providers that met the patients' needs in both a structured, friendly and personable fashion from healthcare professionals (Schnell and Standl, 2006).

Riley et al (2013) successfully showcased tele-monitoring to be a form of communication that focused the patient's relationship with the nurse positively, targeting and tailoring the patient's needs. The method of tele-communication facilitated techniques raising self-efficacy of self-care management. The optimisation of patient knowledge aided in enhanced skills, essential to managing self-care actions and maintenance over a 6-month schedule. Tele-monitoring centered patients to be expert led and empowered with the support of healthcare professionals.

A catalyst to enhanced medication adherence and compliance was education (Wu et al, 2008). The desire to be healthy was a key motivator to patients with HF to take prescribed medicines. HF patients connected knowledge of their illness and symptoms with their medications' effectiveness in decreasing arising symptoms resulting in consistent adherence. Nevertheless, barriers to making connections included limited communication with healthcare providers, forgetting to take daily medications, being unable to financially afford medications, adhering to schedules of timing, understanding side-effects and difficulties in swallowing medicines. The authors of this study identified most importantly the need for healthcare provider assistance in cueing connections for service users with prescribed medication regimes, and optimised health outcomes. Multiple features of this would include informing patients of side-effects, medication schedules and addressing difficulties such as financial support related to purchasing and refilling medication. It was essential this gap was bridged as healthcare providers could largely impact adherence by making connections between medication regimes and better health outcomes. Thus, working closely to address concerns was essential.

Understanding HF and being in control of symptoms aids choice, thus empowering the patient to self-care and promote their levels of well-being. Self-management involved:

- Learning to recognise symptoms
- Responding to symptoms
- Knowing when to seek help
- Understanding and recognising the barriers to managing symptoms
- Consulting medical professionals upon experiencing symptoms
- Managing risk factors associated to HF
- Managing medicines

In most cases the simplicity of the above criteria overrides practice. Enforcing informed decisions relating to self-care was arbitrary. Riley et al (2013) have argued that there was variation in terms of how patients chose to self-manage HF. Typically, patients with a chronic illness received care and support from primary care staff at home for several years (Imes et al, 2011). The role of healthcare providers has shown that with regular contact and support, through assessments, which focused on the health beliefs of patients and monitoring of their physical and mental status solidified the self-care decision-making behaviours of patients

(Tierney et al, 2012; Schnell & Standl, 2006). However, where tailored support was sparse and enabling factors to self-care were poor, satisfaction of self-care deteriorated disengaging active monitoring. Thus, the manifestation of debilitating self-care reduced motivation leading to further complications such as frequent hospitalisation (Siabani et al, 2013).

Self-care management has been a complex and multi-faced phenomenon that required a comprehensive consideration of patients including their emotional situation, psychological characters, physical abilities, family support, living facilities, comorbidities including cognitive function and ability and willingness to learn and adapt. Insufficient knowledge about HF, symptom recognition and barriers of self-care along with hopelessness and psychological problems limited functional abilities for effective self-care. A supportive environment, motivation and adequate care programs using effective educational methods that build self-care skills and utilised culturally specific enablers should be recommended to healthcare providers and families (Baliga et al, 2008).

Obtaining informed consent was a requirement for all research studies in the NHS (National Patient Safety Agency: National Research Ethics Service, 2008). Previous research has suggested that recruiting and obtaining informed consent from minority ethnic groups can be challenging (Bhutta, 2004; Newton & Appiah-Poki, 2007; Helgesson & Eriksson, 2005). Lloyd et al (2008) proposed securing recruitment through audio-recorded methods with a view of bridging the gap between minority ethnic groups who were often excluded from type 2 diabetes research due to perceived cultural and communication difficulties. The authors of the study found improved recruitment rates, proving it to be an alternative and acceptable technique to written consent in study populations where literacy was variable (Akkad et al, 2006).

2.3.2 RISK FACTORS FOR HEART FAILURE

2.3.2.1 HEALTH AND PHYSICAL ACTIVITY

Women were generally considered to be less at risk of developing CHD and HF than men. However, this was not the case for SA women where there was an equal risk (Visram et al, 2008; Reid, 2005). There appeared to be limited research into the reasons why this may be and into factors that may be preventing SA women from progressing with cardiac rehabilitation. There was a consensus that SA women have additional and unique challenges linked to cultural and religious values compared to White-European women.

Research has shown that there were high rates of CVD and CHD among SA people in the UK compared with the majority population (Mathews et al, 2007). According to Matthews et al

(2007), the mortality rate of people living in the UK who were born in the Indian subcontinent was 50%-60% higher than the standard population in England and Wales, and 60-70% higher in Scotland. As a result, it was clear that UK SAs constituted a high-risk group. The reasons for such a high mortality rate have been linked with several factors, including smoking, diabetes, obesity, lack of exercise, poor diet, lower socio-economic status and inequalities in healthcare. In order to reduce the risk of CVD and health inequalities, there needed to be further public health interventions that considered culturally sensitive issues (ibid).

There was also a difference between mortality rates of SA men and SA women: ‘individuals with ancestry in the countries of the Indian subcontinent have a higher premature death rate from CHD than the indigenous population, 46% higher for men and 51% higher for women’ (Visram et al, 2008). In particular, there was a discrepancy between White-European women and SA women. Traditionally, women have been thought to have lower risk of heart disease than men (Visram et al, 2008), but the risk was much higher for SA women to the extent that it was the same as men.

Women differed in their presentations, treatment and outcome of CHD when compared to men (Fransoo et al, 2010). They were more likely to be older (Walling et al, 1988; Szymanski et al, 1993) and less likely to be referred to CR programmes (Ades et al, 1992). Additionally, when they were, they were less likely to attend than men (McGee & Horgan, 1992). This was possibly due to programmes being male-oriented or because of a tendency to select younger, low-risk patients (Schuster & Waldron, 1991). Yet, the functional benefits for women who attended CR were the same for men (Lavie & Milani, 1995). Elderly people did not gain equal access to CR. It was thought that a shortage of resources encouraged selection bias, with older patients losing out to younger patients, thereby reinforcing the false view that older patients would gain less (Masani et al, 1995). What was evident was that information concerning ethnic groups and CR was sparse.

Exercise training was known to reduce the debilitating symptoms of CHF, such as breathlessness and fatigue (McKelvie et al, 2002; Hambrecht et al, 1995; Rees et al, 2004). Recent meta-analyses have also demonstrated better survival and fewer cardiac events among CHF HF patients randomised to training programmes when compared to usual care (Masani et al, 1995; Collaborative ExTraMATCH, 2004; Smart et al, 2004). Over the past two decades, there has been considerable interest in the role of exercise therapy for patients with stable CHF and there was no evidence that exercise programmes can improve exercise tolerance, muscle function and QoL (Austin et al, 2005; Delgardelle et al, 2002). The ExTraMATCH collaborative meta-analysis (Piepoli et al, 2004) concluded that exercise training significantly reduced mortality and hospital admission. The National Institute for

Health and Clinical Excellence guidelines for the management of CHD (National Collaborating Centre for Chronic Conditions, 2003) advocated the adoption of regular exercise as a safe and effective method of treatment for patients with stable CHF. Exercise training improved exercise capacity and health related QoL in patients with NYHA functional status class II or III HF (Rees et al, 2004).

Most rehabilitation programmes were carried out within hospitals with a fixed length of time and location. Most research has been based on structured programmes of between 4 weeks and 1 year (most being 8-12 weeks), with patients attending in a hospital outpatient setting twice or three times a week allowing gradual progression of exercise enabling improvements in fitness and QoL. Extension of rehabilitation programmes beyond 12 weeks reduced the number of patients who were able to access the course and highlights issues of staffing and funding. Nevertheless, such programmes engaged peer support, social contact and more efficient use of staff times.

A small study looking at the effects of a 12-week, supervised, home-based exercise programme in women with stable CHF found improvements in exercise tolerance and QoL compared with a control group (Ades et al, 2013). McKelvie et al, (2002) however looked at continuing exercise at home following an intense programme, but little improvement was found. The main cause for this was patient compliance with the exercise programme, indicating that supervision may be required to obtain optimum benefit. It appeared that supervised, gym-based group programmes have been shown to be effective while home-based rehabilitation programmes were less effective.

In a qualitative interview study guided by the model 'Predisposing, Reinforcing and Enabling Constructs in Educational Diagnosis and Evaluation' (PRECEDE) 16 Canadian SA participants felt positively assured to be involved in a CR programme (Banerjee et al, 2010). Three prominent predisposing factors emerged that appeared to play an essential role in regard to building a firm role to enrol in CR. Participants felt that being informed of CR as a medically supervised programme provided them with assurance that they were in a professional health environment where they would be monitored and prescribed exercise that would be safe. Previous knowledge of CR and an opportunity to be further educated about physical activity encouraged participants to further engage in CR. Enabling factors that enabled facilitation to attend CR was accessible transport, flexible CR classes and cardiologist or physician referral. Reinforcing factors included family and community member support (Crozier et al, 2006), physician support and follow-up, in addition to supportive and caring staff, which enabled positive physical and psychological outcomes as important reinforcing factors in their decision to adhere to the CR programme.

The research had been widely criticised for its focus on mostly white, elderly men (Pattenden et al, 2007), which had produced results that did not accurately represent the UK population. As a result, identifying differences between men and women HF patients and SA men and women HF patients was challenging and problematic. However, some notable differences between men and women have been identified. For example, while HF tended to affect elderly people over 65 years and the onset of HF among women tended to be delayed by up to 10 years compared with men (Sundin et al, 2010). The symptoms of HF among women also appeared to have a greater effect on QoL. The same symptoms of breathlessness, fatigue, oedema and reduced work capabilities lead to an impaired QoL and, as a result, women were more likely than men to develop depression or anxiety. Similarly, Rohrbaugh et al (2002) found that women tended to suffer from increased physical limitations, depressive symptoms, and adverse psychological symptoms. There was strong evidence from clinical research to suggest that women have a higher risk of suffering from psychological and depressive symptoms. However, Rohrbaugh et al (2002) also found that women with HF tended to live longer than men with HF.

There were also some notable differences in terms of how women perceived and made sense of their illness and treatment. Women often felt that their illness made them a burden to others and so may have suppressed the symptoms and avoided asking for help. This led to women receiving less care at home than male sufferers. Women felt that asking for support showed that they have reduced independence and therefore felt guilty about not being able to reciprocate the support. Lip et al (2004) found that SA women, tended to place their trust of the management of their illness in others, notably medical professionals and family members. However, they did admit that this pattern varied according to educational levels and knowledge of disease. Additionally, the results showed 50% of the female SA sample were taking their drugs purely on the basis that their doctor had told them to do so but sadly received less care at home than men emphasising how much SA women trusted others to take responsibility for their illness. It may also tie in with issues of fatalistic and traditional beliefs stemming from religious and cultural practices, but there was no evidence to confirm this link.

According to Sundin, Bruce & Barremo (2010), this tied in with issues of power in that women wanted to feel powerful. The fact that women felt tied by family responsibilities and could see how their illness was limiting their ability to perform household tasks, meant that women suffered from more significant consequences of social alterations and may explain why women have a higher risk of developing depression (Rohrbaugh et al, 2002). This correlated to a study by Paton et al (2006), who argued that women might suffer more than men due to the societal pressures expecting them to continue to fulfil tasks despite their illness. On the other hand, Rohrbaugh et al (2002) also argued that the majority of research had been primarily based on men and so it was not clear how HF affected the quality of life of women because the unique challenges that women encountered were overlooked, leading to poor quality of life.

Evangelista et al (2001) argued that, while HF can often lead to debilitating physical impairment, there appeared to be the same pattern for men and women. One major difference drew upon similar findings by Sundin et al (2010) and Paton et al (2007), in that women tended to ascribe positive meanings to their health, as opposed to men (Jaarsma, 2002; Strömberg & Mårtensson, 2003; Paton et al, 2006). Sundin et al (2010) argued that this positive association tended to lead to an improvement in the patient's physical well-being, evidenced by women having a generally better physical well-being than men.

Research by Pattenden et al, (2007) found noticeable cultural differences among SA HF patients, who generally had a more philosophical approach to treatment and an understanding of death based heavily on religious beliefs. SA patients were also found to follow what could be considered more 'traditional' approaches and attitudes towards treatment. SAs were also found to be worse in terms of functional limitation due to linguistic and cultural barriers and poverty.

SA women have been also found to encounter unique challenges in rehabilitation in relation to physical activity and exercise. Exercise can be challenging for SA women due to religious and cultural barriers (Farooqi et al, 2000). SA research and health care interventions did not take these issues into account and hence were culturally insensitive (ibid).

Research conducted by Sriskantharajah and Kai (2006) and Astin et al (2008) suggested a discrepancy between SA women and the majority population in terms of physical exercise. In particular, the majority of SA women interviewed did not recognise the benefits of physical exercise to improve and limit progression of their disease. Hanif & Karamat (2009) found the same results in a case control study of British SAs and Indian Asians, which showed that twice as many SAs took no physical exercise. Despite there being some similarity in terms of attitudes towards physical activity between SA women and the majority population, such as recognising the importance of losing weight and maintaining independence, there was strong evidence to suggest that there was a significant difference in terms of philosophy. Sriskanthantharajah and Kai (2006) concluded that SA women tended to recognise the importance of being active day-to-day, rather than the 'Western' concepts of organised exercise.

Several reasons were suggested for these differences; particularly that so few SA women took part in regular, organised exercise. Hanif & Karamat (2009) referred to socio-economic status, language barriers and education levels. Interpreters were still not widely available in healthcare except by prior arrangement, and cultural and religious beliefs made it difficult for patients to attend clinics at certain times/days to speak openly to members of the opposite sex, or for women to travel alone to clinic appointments (Hanif & Karamat, 2009).

Cultural and religious beliefs were deemed to be the biggest factor preventing SA participation in Western concepts of organised activity. SA Women, especially from Muslim areas of Pakistan and Bangladesh, were more likely to consider cultural barriers such as religious modesty or avoidance of mixed-sex activity and fear of going out alone as inhibiting factors preventing them from taking physical activity. Cultural factors also extended to shared philosophies among the SA population, who 'share the belief that SAs have a strong work ethic and they take pride in the fact that this is part of their belief system and as a result, it has become almost expected to sacrifice health and physical activity for one's work and family' (Patel et al, 2012, p.780).

Galdas, Ratner & Oliffe (2012) found some major differences between SA women and White-European women when it came to CR. There were also some major cross-gender differences amongst the SA population. Firstly, SA families were found to support men in CR more than women, making the CR process more challenging for women. Although many SA women attempted to make lifestyle changes, external factors, such as reluctance to join mixed-sex exercise groups and concerns about safety walking around inner-city areas (Darr et al, 2008), made this problematic. The SA also reported (ibid) difficulties with clothing requirements for physical activity because they were deemed incompatible with traditional SA dress, including the wearing of long headscarves resulting in a further barrier of SAs to partaking in physical exercise. In addition to these logistical and practical barriers, there was also evidence to suggest that traditional philosophies and ideologies also created problems that prevented these SA women from partaking in exercise (Galdas, Ratner & Oliffe, 2012; Webster et al, 2002). They SA were often found to have a fatalistic attitude towards their recovery and often tied their recovery to fate or to the 'will of God'. Chauhan et al (2010a) found the same theme with SA women often believing the cause of their illness was due to the 'will of God'.

A further barrier for SA women was putting aside the time for organised physical exercise. General observation (McLean & Campbell, 2003) suggested that these SA women, in particular those aged over 50 years, were often busy with maintaining the household, cooking, cleaning and looking after a family. For example, it was common for children to live with their parents well into adulthood until they got married. Even after marriage, it was also common in SA culture for the daughter-in-law to live with her husband's parents. Also, those SAs spent extra time cooking complex meals and hence had less time to dedicate to exercise. These more general cultural differences produced major barriers for SA women.

2.3.2.2 DIET

Eating a healthy balanced diet was essential in maintaining a healthy weight, controlling symptoms and having sustainable energy.

Reducing the amount of salt (2.5grams), controlling fluid intake and regular weigh-in sessions helped with sudden weight gain for a HF patient. Weight gained in HF patients may have been due to water retention, so it was important to weigh daily and monitor fluid retention changes.

Some research has been conducted on the relationship between CHD and diet among SA people (Darr et al, 2008) and how this relationship was maintained among SA women in particular. In general, SA patients were less likely to modify their diet than White-European patients. There were some noticeable differences between SA women and SA men and also between SA women and White-European women. For example, SA women were less likely to recognise the need for them to lose weight than SA men. This was the opposite of the White-European population where women were more conscious about weight than men. Similarly, both SA women and men appeared to be more hostile than the White-European population to the idea of modifying their diet for the sake of their health.

Several reasons for this hostility have been suggested. Heo et al (2009) categorised the decisions to follow or not follow a specific diet into four main factors: knowledge; social pressure and encouragement from others; social situations; and food as a source of pleasure and enjoyment. In terms of knowledge, Heo et al (2009a) found a general lack of knowledge among SA patients (Remme et al, 2002; Lichtenstein et al, 2006; Uretsky et al, 1998), such as good fat and bad fat and appropriate sodium intake. Farooqi et al (2000) however found the vast majority of patients had some awareness of what constituted a healthy diet. There were also some common misconceptions among SA people that since their earlier ancestors did not struggle with CVD and food, which has been passed down for generations, this could not be the cause of heart disease. Another misconception was the absence of meat in vegetarian diets was healthy and a protective factor for CVD (Patel et al, 2012).

In terms of social pressure, there was a lack of a support network in order to encourage SA women to maintain a diet (Heo et al, 2009a; Sriskanthantharajah and Kai, 2006). Consequently, SA women had less incentive to make changes to their diet. Similarly, social situations also affected the feasibility of these SA women to maintain a diet. Even if dietary adaptations were made at home, it was challenging to maintain this diet consistently outside of the home when visiting friends or when attending social events. Heo et al (2009b) used the example of limited availability of low sodium food choices at restaurants and of difficulties finding appropriate foods when visiting others. Finally, many patients found it challenging to modify their diet because of the pleasure they derived from eating certain foods and so for some, the pleasure of eating food was more important than the health benefits of changing their diet. According to Patel et al (2012), ‘food is a central component of SA social gatherings and is another way SA preserve cultural ties to their homeland. At these gatherings, it is considered unacceptable to turn down certain foods, increasing the struggle to maintain dietary change’ (Patel et al, 2012, p. 780).

There were also dietary challenges that arise due to religious reasons (Bahl, 1993). In particular, Muslim patients were forbidden on religious grounds to consume pork and alcohol and so medication that had a porcine or alcohol base, such as capsules prepared with gelatine casings, must not be prescribed.

2.3.2.3 SOCIO-ECONOMIC STATUS

Galdas et al (2012) made generalisations about how the typically lower SES of SAs led to a higher risk of health problems, including diabetes, HF and other cardiovascular diseases. However, these generalisations did not take into account the proportion of SAs from a higher social class or who had a higher income level. There was also no data to show what proportion of SAs as a whole fell into the higher income category or into a higher social class and so Galdas et al (2012) made assumptions based on trends in migrant groups as a whole, rather than based on data specifically relating to SAs. General observations and the idea that SAs had a harder work ethic (Patel et al, 2012), pointed towards the prospect that more SAs had a higher SES compared to other migrant groups. Consequently, this questioned the reliability of studies that make generalisations about SAs based on generic ethnic data.

Lower SES has often been attributed as the major factor affecting access to healthcare services for SA patients. For example, Mathews et al (2007) attributed the high rate of CVD among SAs to lower SES, though this was a gross generalisation.

According to Bahl (1993), ‘it is recognised that a large proportion of the immigrant population lives in relative deprivation’ and ‘where there is deprivation, there is poor health, irrespective of background and ethnicity’ (Bahl,1993, p.15). Bahl (1993) commented on how healthcare services must recognise cultural differences, but this again marked non-whites as the ‘other’ that posed a problem for the established ‘indigenous’ system. Therefore, in order for the same provision to take place, Bahl (1993) argued that cultural differences must be set aside. In fact, culture might not be a relevant issue for equal access to healthcare services because the inequalities, by Bahl's (1993) own admission, were due to socioeconomic factors and poverty, which were 'irrespective of background and ethnicity' (1993, p.15).

Taylor et al (2013) argued that access to healthcare services is a problem for ethnic minorities because they had a lack of knowledge and had a language barrier compared to the majority white population. Taylor et al (2014) go on to describe instances where migrants had no English, no literacy and where they did not understand the role of interpreters, paramedics and other healthcare professionals. While this might be the case for some recent migrants, it was unlikely to be the case for people who had been in the UK for some time. Their research gave no indication of the demographic of their sample and so it was not possible to discern whether or not the sample included patients who immigrated to the UK during the two main waves of immigration in the 1950s and 1970s. As a result, the idea that there was a lack of knowledge might not be such a huge inhibiting factor as originally thought. Similarly, SAs might not have excellent English, but social adaptations by way of interpreters could be made to make healthcare services accessible. Also, lack of English did not entail lack of knowledge or education, as Taylor et al (2014) suggested. Taylor et al (2014) provided one of many examples of how the literature was biased towards the perspective of the majority population, which perceived all migrant groups as the 'other'. Gerrish (2000) argued that statistical research relating to ethnicity was vital in order to inform policy and to adopt a social model of improving accessibility to health services. She argued that research tended to 'blame' culture (Fleming & Gillibrand, 2009) and offered culture as the explanation of problems, implying that minority ethnic communities should adopt White cultural practices in order to overcome health disadvantages. However, 'this perspective fails to recognise that to discover why different ethnic groups have different experiences of health and identify strategies to overcome inequalities, there is a need to disentangle influences of racism, education, employment and social deprivation from cultural concerns' (Gerrish, 2000, p.919). This conceptual demarcation of the 'self' and the 'other' was known as 'ethnocentricity' (ibid): the tendency to evaluate other ethnic groups from the perspective of one's own culture. As a result, such an ethnocentric approach affected the research aims, designs and methods, thereby questioning the reliability and validity of the research findings.

Gerrish (2000) concluded that studying so-called 'cultural differences' ignored the more important issues of education, social class and income levels, which were unrelated to race and ethnicity. She argued that the ethnocentric point of view of current research, by focusing on issues of ethnicity and race, was a means to class non-whites as the 'other' and to justify where there was a problem with access to healthcare.

2.3.3 HEART FAILURE AMONG SOUTH ASIANS

2.3.3.1 SOUTH ASIANS

South Asian (SA) individuals living in the UK had higher cardiovascular mortality and morbidity compared to the White population. SAs had a 50% greater risk of dying prematurely from CHD. Furthermore, the difference in death rates amongst HF patients was greater for SAs than the rest of the population as the death rate from CHD was not decreasing amongst SA patients as it was with the rest of the White population (Goulding et al, 2010).

The risk factors associated with HF included ischaemic heart disease (IHD), hypertension and diabetes. However, it can be argued that the SA ethnicity may also be a risk factor for HF. Patients of SA descent had a significantly higher risk of developing diabetes, which is estimated to be around two times more likely than in Europeans. HF was twice as likely in people who had diabetes and this likelihood increased to over ten times the chance if the patient was less than 45 years of age. Moreover, SAs had a greater prevalence of insulin resistance and impaired glucose intolerance which were both risk factors for HF. SAs also had less favourable lipid profiles and lower high-density lipoprotein cholesterol concentration and higher triglyceride concentrations than Europeans. These lipid profiles in SAs were associated with CAD development, as well as acute MI and HF (Tierney et al, 2012). A comparison of the literature in relation to ischaemic aetiology within the SA population and White patients showed that 15% of White patients had acute MIs compared to 27% of SAs, whereas 25% of White had other coronary diseases compared to 29% of SAs (Blackledge et al, 2003). Singh & Gupta (2005) too found similar differences, 48% of White patients with ischaemic HF in comparison to 59% of SAs. For Sosin et al (2004a), 70% of White patients as having ischaemic HF compared to 79% of SAs. Finally, a comparison at IHD stated that 57% of White patients had IHD compared to 69% of SAs (Kaul et al, 2011). It was clear; therefore, the risk was much greater within the minority population as compared to the White population.

Moreover, SA HF patients tended to be younger than White patients and SA patients had better survival rates as compared to the White patients, although after six years the survival curves of SA and White patients started to converge. This was mainly due to the younger age of SA patients despite having the prevalence of diabetes and hypertension (Tierney & Deaton, 2013). Studies have been conducted to compare the survival rates of White and SAs with HF. Lip et al (1997a) found that in-patient mortality rates were 21% for Caucasian patients and 13% for SAs, which showed a non-significant difference. SAs were found to have a reduced risk of death from HF when followed up for at least six months (Blackledge et al, 2003a) and

SA ethnicity was an independent predictor of survival when followed up by an average of 1,257 days post admission (Newton et al, 2007). However, ethnicity was not a significant predictor of mortality at the eight-year follow up (Sosin et al, 2004b). Furthermore, there was no difference between the ethnic groups in relation to the risk of death during hospitalisation (Singh et al, 2005).

The lack of data for SA patients with HF meant that evidence-based recommendations for SAs were severely limited. However, there has been some evidence to suggest that there were ethnic differences in response to medication. Therefore, treatments that might work for White populations might not work on SA patients. There were no studies comparing approaches of pharmacological treatment between SAs and White populations with HF. Therefore, no recommendations or suggestions could be proposed on how best to help the SA population in terms of HF medication. Treatments that might be effective for both SA and White patients were revascularisation and coronary artery bypass grafting for ischaemic cardiomyopathy especially if angina symptoms were present. Studies have shown that revascularisation rates were similar or higher for SA patients compared to White patients. This differed to another study conducted, which suggested that there were no differences between SAs and White populations in terms of revascularisation rates when undergoing coronary angiography. The difference arguably was not down to ethnicity but due to age with SA patients having a lower rate than White populations. Revascularisation might be less likely amongst SA patients as there was a perception that their coronary arteries were smaller, with more diffuse disease and this would make procedures difficult (Tierney et al, 2012).

Comparisons of the studies regarding the treatment received by White populations and SAs have shown that in the five years prior to admission 3.3% of SAs and 2.1% of White populations had undergone a revascularisation procedure (Blackledge et al, 2004b). At admission, drug treatment was similar for both groups except White patients were more likely to be on diuretics and digoxin whereas SAs were more likely to be taking beta-blockers and a calcium channel blocker (Newton et al, 2007). Finally, within the one year follow up a higher proportion of SA patients (25%) compared to White patients (14%) had undergone cardiac catheterisation. There were also more SAs who had undergone coronary artery bypass graft (CABG) (Head et al, 2013).

A further comparison between SA and White patients, which is relevant to HF, was body composition. SA patients tended to have thinner limbs but carried more weight around the trunk. SAs might have relatively low levels of obesity compared to White populations, but SAs tended to have a higher waist to hip ratio. This was also affected by levels of physical activity amongst SAs, which were considerably lower than White groups. Treatment for HF involved lifestyle changes and attempts to modify patients' behaviour. Therefore, attention should have been given to managing weight and glucose levels amongst SAs, to reduce the onset of HF. This might be in the form of dietary interventions or encouraging physical activity in a culturally sensitive manner (Tierney et al, 2012).

Furthermore, SA patients with a more fatalistic belief to HF tended to seek medical help later compared to patients who deemed themselves as responsible for their own wellbeing. Tierney et al (2012) found 65% of British SA patients with HF felt God/fate controlled their health compared to 33% of White patients. 62% of the SA patients were not aware that their primary diagnosis was HF whereas only 14% of White populations were unaware. Moreover, half of the SA patients did not think HF was severe compared to 19% of White populations. Finally, 35% of SAs felt they had enough information regarding HF whereas 79% of the White populations felt equipped with knowledge. Such beliefs might have an effect if the individual decided to attend CR and stick to dietary and physical changes. This was important as SA patients were less likely to attend CR than White patients. This might be attributed to some SA patients being unable to speak English and therefore being unable to access medical information. However, SA patients had rated healthcare less favourably than White populations, which might be due to differences in health expectations and being unable to access services due to language barriers (Tierney et al, 2012).

HF was a major and increasing burden all over the world (Lloyd-Jones et al, 2002). There were no reliable estimates of HF incidence and prevalence in South Asia, there were only some projections based on prevalence data from Western countries (Huffman, 2010; Pillai et al, 2013). South Asia was both the most populous and the most densely populated geographical region in the world. The SA countries, which include India, Pakistan, Bangladesh, Sri Lanka, Bhutan, Maldives and Nepal, were the home to one-fifth of the world population. The countries in this region were undergoing epidemiological transition and were facing the double burden of infectious and non-infectious diseases (Boutayeb, 2006).

Pillai et al (2013) highlighted the burden of HF and discussed its epidemiology SA today. The prevalence of HF, which was predominantly a disease of the elderly, was likely to rise in SA due to the growing age of the population. Patients admitted to hospitals were relatively younger than their Western counterparts. The aetiology of HF in this region was also different from the Western world. Untreated congenital heart disease and rheumatic heart disease still contributed significantly to the burden of HF in this region. Due to epidemiological transition, the prevalence of hypertension, diabetes mellitus, obesity and smoking has been on the rise. The authors reported this was likely to escalate the prevalence of HF in South Asia. Issues related to HF management related to accessibility and affordability in that SA patients had uneven and limited access to healthcare. People living in remote villages, high lands and islands in this region often had limited access and issues relating to affordability. In Argentina, China, India and Tanzania, it was found that 10%-12% of the patients did not take any medications due to an inability to afford medications (Huffman et al, 2011). HF usually required lifelong medications.

Multiple readmissions were not only a powerful marker of poor prognosis and of poor life quality but they also led to increased costs to the health care system (Cleland et al, 2003a). In view of this fact, outpatient management programs might be a suitable strategy for managing the burden of HF, in addition to Implantable Cardioverter Defibrillators (ICD). To reduce the burden of HF, the reduction of risk factors namely, hypertension, diabetes, smoking and obesity must be controlled in addition to providing advice regarding salt reduction, regular physical activity and healthy diet. Providing cardiac rehabilitation would improve clinical outcomes (Fonarow et al, 2007a; Fonarow et al 2007b; Abegunde et al, 2007).

The authors of the study stressed the need for large multi-centre representative observational studies to quantify the disease burden, and to identify the aetiology of HF in South Asia. The authors made clear the need for cardiovascular clinical practice guidelines, which would offer nationally representative quality improvement initiatives to improve care for HF preventing the burden of HF significantly. Establishing HF clinics and initialising nurse and primary health care worker-based management programs would help in reducing the disease burden in South Asia, (Pillai et al, 2013).

An overwhelming amount of concern relating to HF within the SA population had outlined the complexity of the findings, similarities, differences and gaps in the literature. This has demanded further insights into the experiences of Pakistani HF patients specifically and their perspectives, an area of particular relevance to this study. This provided support for the aim of this study, which has been discussed in depth later in this chapter.

2.3.3.2 LANGUAGE AND CULTURAL BARRIERS

Many British Pakistanis from the Azad Kashmir and Punjab regions of Pakistan spoke a regional dialect or language of Punjabi, Mirpuri/Pahari or Hindi at home and might have some knowledge of Urdu (Shaw & Ahmed, 2004). Also, many might have low levels of literacy and education. However, most of the second generation who were born and raised in the UK were bilingual or multilingual in English and their home language(s). Although, Punjabi and other regional languages might be the mother tongue, most Pakistanis in the UK seldom used those languages as a written form of communication and preferred to use Urdu instead, as it was the only official and national language of Pakistan.

Language and cultural diversity were important variables, which affected the way the Pakistani population accessed healthcare. Interactions between healthcare providers and Pakistani patients could be seen as inter-cultural communication as this involved face-to-face communication between two individuals with different cultural backgrounds (Gudykunst, 1991 cited in Cortis, 2000a). However, arguably all interactions were inter-cultural as culture incorporates variables such as gender, social class, ethnicity and language (Cortis, 2000b). In healthcare settings, translation of materials, questionnaires and interviews from English into other languages had been hindered by cultural hegemony as well as a lack of transference of concepts from one culture to another. This was further exacerbated by an expectation from healthcare providers that the patients would disclose personal information and understood complex language which was not always accessible to the less educated (Hanna et al, 2008). For example, written information could be useful in summarising issues with healthcare providers. This should be jargon free and in plain English. However, this was reliant on the literacy levels of the patients and could be affected by the efficiency of the translation (Shaw & Ahmed, 2004).

There was often less clinical data among Pakistani patients in healthcare settings due to language difficulties and a lack of cultural awareness (Chauhan et al, 2010). In addition, poor recording might also be due to institutional failings such as inadequate staff training and a lack of interpreters (Chauhan et al, 2010a). There were many barriers that affected collecting accurate data on HF within the Pakistani community, with one main barrier being the view that methods which have been used for the indigenous population were applicable to the Pakistani population of the UK (Hunt & Bhopal, 2004).

Language difficulties for HF patients who did not speak English made it difficult for said patients to convey their feelings and emotions. Language barriers tended to be higher in Pakistani patients who were over the age of 65. For women, this language barrier tended to be of a higher proportion (Jolly et al, 2004). Therefore, when accessing communication and written materials in healthcare settings (because many of the first generation were not able to read and write Punjabi or other regional languages nor read and write English fluently) most of them would need interpreters/translations to overcome this barrier (Hanif & Karamat, 2009). Therefore, the need for a high-quality interpretation service for all patients was of utmost importance (Bahl, 1993).

Better access to interpreters should be the primary focus for CR services so that Pakistani patients had a better understanding of how CR worked and to breakdown the language barriers present (Banerjee et al, 2010a). This being the case, many Pakistani patients with HF who did not attend CR cited the reason for non-attendance as the inability to speak English. Pakistani patients were often not given video or audio taped rehabilitation materials in their own language and many did not have access to an interpreter. This inability to speak English also caused problems between the healthcare provider and the patient, as the patient was unable to ask questions about his/her condition. Furthermore, assumptions were often made about Pakistani HF patients based on their appearance and this could often lead to communication issues (Galdas et al, 2011).

An inability to speak English caused many Pakistani patients to be severely disadvantaged in accessing healthcare. For example, they faced obstacles such as not being able to explain pain, were unable to arrange appointments and were unable to understand how to take their medication. This language barrier often meant that health professionals had to adopt strategies such as limiting and repeating information (Taylor et al, 2014). Language issues during consultation could also occur where information could be lost due to misunderstanding. Differences in phrases and terminology coupled with a lack of basic knowledge about the workings of the body could cause a breakdown in communication and understanding. Therefore, healthcare providers needed to check verbally whether the Pakistani HF patient had understood what had been said (Bahl, 1993b). It was essential an interpreter accompanied the patient in order to avoid any miscommunication.

This lack of functional English could lead to patients relying on family members or trained interpreters although this in itself posed difficulties as there were shortages of trained interpreters. This often meant that untrained interpreters were used but this could result in mistakes and confuse the HF patient about their condition (Tod et al, 2001a). Many Pakistani patients with HF had spouses who did not speak English, and this caused issues with communication between healthcare professionals and their spouses. This often meant that non-English speaking wives relied on their children or husband to explain what differences they needed to make at home in relation to the HF diagnosis. Children often acted as interpreters, which could cause friction between the children and patient as it breached conventional family roles and privacy issues. This could occasionally mean that family members withheld information regarding the patient to prevent the patient feeling alarmed or scared (Astin et al, 2008a/b). HF patients' children were often used to interact with health professionals in order to provide their parents with HF advice. The lack of communication with the actual HF patient could mean there was no opportunity to highlight the importance of family involvement in HF treatment (Galdas, 2011). Although children were often used, Pakistani patients with HF who cannot speak English often found that their language barriers severely affected their wellbeing and daily life often disempowering them and hindering social integration (Taylor et al, 2013).

2.3.4 PATIENT'S PERCEPTION OF HF (QOL)

Patients with HF have multiple readmissions to hospital, a poor diagnosis and varying quality of life QoL (Krumholz et al, 2002). It was a common chronic condition associated with high levels of morbidity and mortality. The incidence of HF had been rising in the UK and there had been a growing concern about the health, social and psychological needs of people experiencing HF and their family caregivers (Cowie et al, 1997a). Living with HF had been a complex, dynamic process with frightening symptoms and complex medications, which often resulted in depression and anxiety, and a loss of role and functional abilities resulting in poor QoL.

Quality of life was the general well-being of both individuals and societies, outlining negative and positive features of life. It observed life satisfaction, including physical health, family, education, employment, wealth, religious beliefs, finance and the environment. It had a wide range of contexts, including the fields of international development, healthcare, politics and employment.

According to the World Health Organization (WHO), QoL was defined as:

'the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals.'

Quality of Life has been a subjective, multi-dimensional concept that has been based on an individual's perception of his own health in relation to physical and psychological factors such as social support, capabilities and daily activities. The SOLVD (Studies of Left Ventricular Dysfunction) investigators defined QoL as a construct containing global aspects of general life satisfaction, current life situation, and dimensions of physical function, emotional stress and social perceived health (Riedinger et al, 2001). In relation to HF, QoL can be viewed as how the illness influenced one's physical and emotional well-being, as well as how it impacted one's social life (Riegel et al, 2008). HF was known to significantly reduce QoL, which was often related to high hospitalisation rates and increased mortality. Moreover, compared to the general healthy population, HF patients had a reduced QoL due to their physical functioning, lack of a role and their social functioning (Jaarsma, 2008). However, QoL was subjective and could not be solely based on clinical and psychological assessments as many patients who had HF had differing views on their QoL (Heo et al, 2009a).

Patients' perceptions of QoL could be divided into three categories: performing physical and social activities, maintaining happiness and engaging fulfilling relationships. For example, physical symptoms such as shortness of breath, fatigue and nausea reduced their view of QoL. Furthermore, many felt that their physical condition, including their heart function, impaired their QoL and limited their daily activities. This could be improved by self-care behaviours such as a low sodium diet, regular exercise and taking medication which was seen to improve QoL as adherence to treatment was seen to increase QoL (Heo et al, 2009).

Psychological factors also affected how patients perceived their QoL, as a good mood and a positive outlook on life could improve their QoL dramatically. HF QoL did not mean the absence of psychological stress but being able to seek happiness and enjoy spending time with others helps. Patients often maintained a good QoL by considering the worst outcome and comparing their situation with others less fortunate. However, many patients felt like a burden to their family, which added to the stress they felt and significantly reduced their QoL. HF patients' QoL was also affected by their economic status with money problems often reducing their QoL. Many patients had trouble affording medication or had to give up work due to their illness and this could negatively affect their QoL (Mangalore & Knapp, 2012). Furthermore, social factors also affected their QoL especially social support. Patients often felt their QoL was better if they had material and personal support from others (Outten et al, 2009; Almeida et al, 2009; House et al, 1988). Moreover, some patients also felt that having a supportive environment where their needs could be met greatly improved their QoL. The perception of QoL could also be affected by spirituality with faith and praying being important factors for some patients (Heo et al, 2009).

In relation to ethnicity, health related QoL was seen to be significantly less. This was mainly due to the unequal burden of chronic illness, which had seen ethnic groups having more symptoms and worse functional disability (Riegel et al, 2008). As QoL was subjective and characterised by a range of positive and negative attributes that characterise an individual's life, culture was therefore an integral part of this assessment. A model used to assess health related QoL (HRQoL) was the traditional HRQoL model which included: socio-ecological, cultural, demographic and healthcare system contexts; general health and co-morbidity; cancer-related medical factors; health efficacy; and psychological well-being. This often had varying domains amongst ethnic groups. However, care must be taken so that groups were not stereotyped. Generally, ethnic groups tended to fall under the socio-economic standard (SES); this was especially the case for British Pakistanis. Lower SES was associated with poorer survival rates and was a risk factor for low QoL. Low SES individuals had limited access to the healthcare system due to lack of information, education and language barriers. British Pakistanis often had difficulty maintaining a patient-physician relationship due to linguistic diversity and this lowered their QoL (Macabasco-O'Connell et al, 2011). There was also research which suggested that ethnic minorities received less and different care which again severely impacted their QoL. Furthermore, ethnic groups were more likely to place higher importance on spirituality with religious beliefs being an important coping mechanism for many ethnic minority HF patients (Mir & Sheikh, 2011). Spirituality had often given optimism and hope to patients, despite their diagnosis and debilitating symptoms, thus improving their QoL (Ashing-Giwa et al, 2006).

Gender also played a role in HF patients' QoL. Generally, women with HF had lower QoL in comparison to other women, as women with HF tended to have more anxiety, depression, and reduced social activities. Tests which had been completed to assess the impact of HF on QoL included Profile of Mood States Inventory (POMS), which measured vigour, anxiety and depression, the Functional Status Questionnaire (FSQ), which measured activities of daily living (ADL), and social function and the Symptom Scale (SS), which measured the frequency of dyspnea, dizziness and chest pain. When assessing the data of these tests women were found to have worse vigour, social activity, intermediate ADL and general wellbeing. Female HF patients often rated themselves as moderately anxious or hostile with moderate depression, which reduced their QoL. There was also a trend that women with HF often believed that they were not healthy enough to perform normal activities. Women often had high physical symptom impact and poor perceived physical health status. Furthermore, women with HF did not often participate in rehabilitation exercise regimes or withdrew from them early resulting in a lower QoL (Riedinger et al, 2001).

In comparison to men with HF, women still tended to have a lower QoL. This arguably could be attributed to the severity of the illness as women often developed the illness later in life and had a longer lifespan than men. However, even when women and men with HF were assessed at the same period of life and with the same severity of the illness, women still tended to have a lower QoL and still had less social activity than men. Women with HF were known to exercise significantly less than men and women often had worse physical and social functioning than men. Even when socioeconomic factors were controlled, women still had a lower QoL than men and lower scores for physical functioning and vitality. It may be viewed that men would do less physical activity once they reached retirement yet women continued to perform household related activities and care-giving, therefore women with HF may have noticed how their HF symptoms impacted and interfered with these activities more so than men (Riedinger et al, 2001).

Quality of life was the general well-being of both individuals and societies, outlining negative and positive features of life. It observed life satisfaction, including physical health, family, education, employment, wealth, religious beliefs, finance and the environment and had a wide range of contexts, including the fields of international development, healthcare, politics and employment.

The measures of QoL in their nature were linear, objective and offered a snapshot of functional overviews as opposed to being patient led and subjective showcasing the voice of the patients. Patients faced multiple challenges such as depression, hostility and psychosocial adjustment to illness. The inclusion of quality of life as an outcome measured in any evaluation of treatment efficacy was imperative if interventions were to improve the quality of life for patients with advanced HF (Dracup et al, 1992).

Knox et al (2016) investigated the effectiveness of telemedicine in the treatment of HF and reported that telemedicine significantly increased overall QoL in patients receiving HF disease management, providing preliminary support for the use of telemedicine. Though statistically the results of the randomised controlled trials were non-significant SMD 0.23, (95% CI 0.09–0.37), p = 0.001), positive trends were observed for physical QoL. Moderator analyses indicated that telemedicine delivered over a long duration (≥52 weeks) was most beneficial compared to usual care of physical well-being. Telemedicine significantly increased overall QoL in patients receiving HF disease management of HF without jeopardising patient well-being.

HF has been a chronic disease that compromised patients' QoL. Interventions designed to reduce distress and improve disease self-management were much needed. Monitoring and improving QoL was an important aspect of the clinical management of HF that can reduce disease burden and help improve clinical outcomes in this vulnerable patient population.

The well-being of life and optimal satisfaction of health was an important aspect of daily life. Understanding the Pakistani communities' QoL measures was imperative as it offered an insight into the enablers and barriers that both enriched and detracted pathways of effective self-care behaviours (Mygind et al, 2013). Upon identification, extracting features that observed QoL measures enabled healthcare providers to hone in on improving elicited cultural and religious appropriateness relating to QofL for the Pakistani community and avoiding discrimination and exclusion (Kirmanoğlu & Baslevent, 2014). Though standardised QoL measures did not reach out to the Pakistani communities specifically, what they did offer was information that could be used as a baseline that could then address cultural and religious appropriateness that would reach out to specific features for the Pakistani community offering a fuller understanding. The relationship between QoL measures and functional status (NYHA) and elicited behaviours might not always mediate efficacy with the Pakistani community, however appropriate person centred styles and dimensions that elicit understanding incorporating cultural and religious appropriateness were pivotal as they would conjure outcomes that integrated positive self-management behaviours and QoL (Uzark et al, 2016).

2.4 DISCHARGE AND POST-DISCHARGE

The discussion so far has focused on the cross-cultural barriers and factors that may affect the risk of SA people acquiring HF. Many of these factors were a result of lifestyle choices and, paradoxically, it was also these lifestyle choices that served as the main barriers in the treatment of HF.

The themes of cultural and linguistic barriers also existed for patients post discharge from hospital. In order to understand the challenges for SA patients post-discharge, issues of readmission, CR, family caregivers and service provision have been discussed in depth.

2.4.1 MEDICATION

Knowledge and understanding of HF appeared limited. Medication-taking was usually not based on a full understanding of the condition, of the causes and of the role of medication in reducing the symptoms. Medication was usually visualised as ‘pills’ or ‘tablets’ to be taken. Patients’ understanding ranged from a vague sense that the pills were doing good, to a feeling that they did not know if they were doing any good but took them because they trusted their health professionals who had prescribed them. Medication was taken at varying times by different patients, thus the patients and family caregivers described two related tasks, remembering to take each drug on a daily basis at the appropriate time and, over the longer term maintaining a supply of drugs. Patients reported concern over remembering whether all medication had been taken, the complex logistics (managing different numbers and types of medication at different times of day) and running out of medication. They also recognised that the dosage of the pills could be changed, and this led them to understand that there was ‘flexibility’ in pill-taking.

To deal with the complex task of taking and managing medicines, patients developed their own strategies, which involved the use of both reminders and routine. Patients reported two forms of ‘low concordance’. The first related to respondents deliberately not taking their medication when they should have. Reasons presented for this action included imminent attendance to at social events, visits to places where toilet facilities were unknown or long journeys. Adjustments included reducing doses, not taking diuretic altogether or taking it at an earlier or later time. Patients spoke of a second form of low concordance, which was most likely to occur when routine of management was broken, and they forgot to take them. The circumstances they described were clustered around participants being in unusual places, being distracted or absorbed in activities such as a day trip away, a wedding or other social event. On these occasions, patients reported that the established routines were broken and back up strategies were less likely to be used.

Both family caregivers and patients understood the process of learning management strategies being an essential part of living with chronic disease. Learning how to manage medication was ‘learnable’ and hence ‘teachable’. Family caregivers engaged in strategies and routines with their partners which helped them to form effective management strategies together.

The theoretical approach taken in this study (Reid et al, 2006) has allowed patients to use their own words to describe their approach to the complexities of the medication-taking. The study has illuminated an alternative understanding of the biomedical (Strömberg et al, 2003; Gray et al, 2001; Zambroski, 2003; Ekman et al, 2000). The results indicated that successful concordance results from the establishment and maintenance of routines and fall-back strategies. Rather than low concordance equating with a lack of commitment to medication-taking, it primarily resulted from these routines breaking down, often from events in their lives, which distracted them from their regimen. The findings therefore suggested that concordance was not fixed over time as one rate, but depended on the daily circumstances of the patients, their medication and the broader context of their lives. The authors showed that the respondents in the study adjusted their medication to fit into the broader demands of their lives even if this meant going against the wishes of their health professionals (Mårtensson, 1998).

Compliance with medical treatment was likely to be improved if patients had a better knowledge and understanding of the drug, its benefits, and its side effects (McCormack et al, 1997). The views of family and friends, societal pressures and a patient’s own cultural or ethnic background also influenced compliance. Indeed, ethnic group was an important factor especially if language difficulties were involved (Ziguras et al, 1999; Hellman et al, 1997). Patients with chronic cardiac disease conditions, such as atrial fibrillation, often had very limited knowledge of the disease process, as well as its consequences and the need for long term treatment (Lip et al, 2002; Lip et al, 2003).

2.4.2 RE-ADMISSION

Hospital re-admission rates for HF patients remained high with an average of around 40% of HF patients being readmitted within six months after their first admission. This readmission rate could vary between 25% and 50% within the first six months; however, this rate amounted for approximately 70% of the cost for HF treatment (Annema et al, 2009). Moreover, hospital discharges for HF had increased by 171% over the past three decades (Rosamond et al, 2008). Despite the fact that disease-management programmes appeared to be a promising start to reducing readmission rates, the number of HF patients still remained high. This may have been due to the fact that disease-management programmes provided easy access to health-care providers for HF patients (Annema et al, 2009). In fact, 50% of HF readmissions were preventable with 55% of these being due to worsening symptoms (Braunstein et al, 2003), which were mainly linked to poor self-care routines (Bennett et al, 1998).

Other factors that might influence hospital readmissions were demographic, physiological and psychological along with patient functioning and the availability of professional and non-professional support. Around 40% patients who had been readmitted to hospital attributed this due to the worsening of HF symptoms. Furthermore, other medical health problems played a major part in hospital readmission (Annema et al, 2009). Braunstein's study (2003) found that 40% of patients with CHF had five or more non-cardiac co-morbidities and this group accounted for 81% of the total inpatients' hospital days by patients with CHF and this risk of hospitalisation increased with the number of chronic conditions. (Hamner & Ellison, 2005). Medical issues such as arrhythmia, ischemia, pulmonary disorders, renal insufficiency and anaemia were all related to hospital readmission. Medication also played a vital role in readmission rates with non-adherence to fluid and medication accounting for around 13%-26% of readmissions (Annema et al, 2009). Furthermore, although angiotensin-converting enzyme use and intermittent positive inotropic infusions reduced readmission rates for HF patients, this did not decrease mortality. The effect of beta-blockers was not so clear with some arguing that they reduced readmission with other arguing they increased the rate of hospital readmissions (Hamner & Ellison, 2005).

Furthermore, medical management also played a role in hospital readmission rates for HF patients. Inappropriate medical discharges and outpatients' management contributed to hospital readmission (Hamner & Ellison, 2005). Insufficient medical help accounted for around 2%-7% of hospital readmissions (Annema et al, 2009). With this in mind, a multidisciplinary disease management approach should be put in place, which decreases the length of stay in hospital and reduces the readmission rates whilst improving QoL and prolonging survival (Hamner & Ellison, 2005). A lack of knowledge by HF patients often means that they asked for medical help too late, accounting for around 18% of readmissions. This often resulted in inadequate prescription planning or could cause pacemaker problems, which severely reduced QoL and meant that patients were more likely to be readmitted (Annema et al, 2009). Patients often felt that readmission might have been preventable (23%) with advising and counselling being an optimum intervention to prevent readmissions along with more follow up visits and seeking medical help sooner (Annema et al, 2009).

Psychological problems involving multiple readmission rates were due to symptomatic pains and aches, anxiety, insecurities, depression, substance abuse and cognitive disorders. Furthermore, psychosocial factors such as lower income, lack of social support and single marital status were associated with increased readmission rates (Annema et al, 2009). However, some studies have suggested that HF patients living with family members have a higher rate of readmission compared to those living alone. This could be due to stress worsening CHF or that family members were more in tune with the patient's changes in behaviour and encouraged them to go back to hospital should anything occur out of the ordinary (Hamner & Ellison, 2005).

SA HF patients in the UK had a considerably higher rate of readmission to hospital compared to White populations. SAs between 60-79 years of age were five times more likely to present HF at hospital than their White counterparts. Despite their younger age, SAs had 55%-60% more hospital readmissions than the White population. This might be due to the higher prevalence of CAD or the fact that SA patients tended to have more co-morbidities such as diabetes. Even though SAs presented HF at a younger age they had more high-risk features at hospital discharge. For example, SA patients had significantly lower levels of haemoglobin and higher levels of urinary albumin excretion. Renal failure in SA patients might account for increased likelihood of diabetes, which was a risk factor for further cardiac problems.

Furthermore, SA with mild to moderate congestive HF had higher plasma leptin levels compared to White populations, which was associated with insulin resistance, another contributing factor to hospital readmission. Furthermore, language issues might be a cause for hospital readmission as one study found that 61.8% of SAs were not aware that their primary diagnosis was HF and three times more often did not have enough information about their drugs causing more hospital readmission. Moreover, SA HF patients were more likely to believe in God and fate controlling their condition with over 64% believing this, and this may account for more readmissions as they may rely less on medical advice (Shantsila et al, 2011).

2.4.3 CARDIAC REHABILITATION

Cardiac rehabilitation (CR) has been a secondary prevention strategy that was defined by the World Health Organisation in 1993 as:

'…the sum of activities required to influence favourably the underlying cause of the disease as well as the best possible, physical, mental and social conditions, so that they (people) may, by their own efforts preserve or resume when lost, as normal a place as possible in the community. Rehabilitation cannot be regarded as an isolated form or stage of therapy but must be integrated within secondary prevention services of which it forms only one facet.' (World Health Organisation, 1993).

CR has been a multidisciplinary process, requiring a range of healthcare skills to bring together medical treatment, educational, sexual and vocational counselling, exercise training, risk factor modification and secondary prevention (Thompson & Bowman, 1996).

CR has been an active process that took place after a person has a heart attack or other heart treatments, such as surgery or angioplasty. The aim was to restore a person to, and maintain him or her at, a best possible level of physical and mental wellbeing (See Appendices 11.24). It required people to assume responsibility for their own health and wellbeing, and to realise their potential to lead an active life. There have been four phases to CR (NICE CG48, 2007).

Phase 1

This phase occurred when a person was an inpatient at hospital.

Many issues were considered during this phase. These included reassurance, risk factor assessment and modification, education for the patient and his/her family and discharge planning. A cardiac rehabilitation nurse would spend time with the patient and their family. This was usually spread over the duration of the hospital stay. The patient would be asked what they thought had caused their cardiac event and to discover the patient's knowledge base and misconceptions. Also discussed were the disease processes, the patient's individual risk factors, medication, chest pain management and employment. Apart from verbal communication, a video and leaflets were used. If a patient had had a heart attack, the Hear Manual or the hospital's own package would be given.

The Heart Manual was a six-week rehabilitation programme for patients recovering from a myocardial infarction (MI). It consisted of a workbook, in six weekly sections, and included a phased programme of health education, home based exercises and stress management. A CD was also provided and contained a programme of relaxation exercises, a scripted interview between a doctor and a patient, and a talk by a doctor targeted at the patient's partner or family member. It had been shown, in major clinical trials that patients using the Heart Manual had improved psychological adjustment at one year with fewer readmissions to hospital within the first six months.

Those patients who were not suitable for the Heart Manual, such as patients who were physically unable to exercise or those with severe HF, received the hospital's own package.

Families were involved as much as possible. Prior to discharge the patient would be informed when they would be sent for to attend hospital for a cardiology review. He/she would also be informed of the Primary Care staff involvement at home and would be given a contact number for the Rehabilitation Team.

Phase 2

This was the early post-discharge phase.

Members of the Primary Care team based in General Practice, who were trained as Heart Manual Facilitators, provided support during this phase. They visited the patient and their family at home on several occasions, reinforced lifestyle risk factors, monitor anxiety and depression levels and generally supported the patient and their family. This support continued for approximately three months.

Phase 3

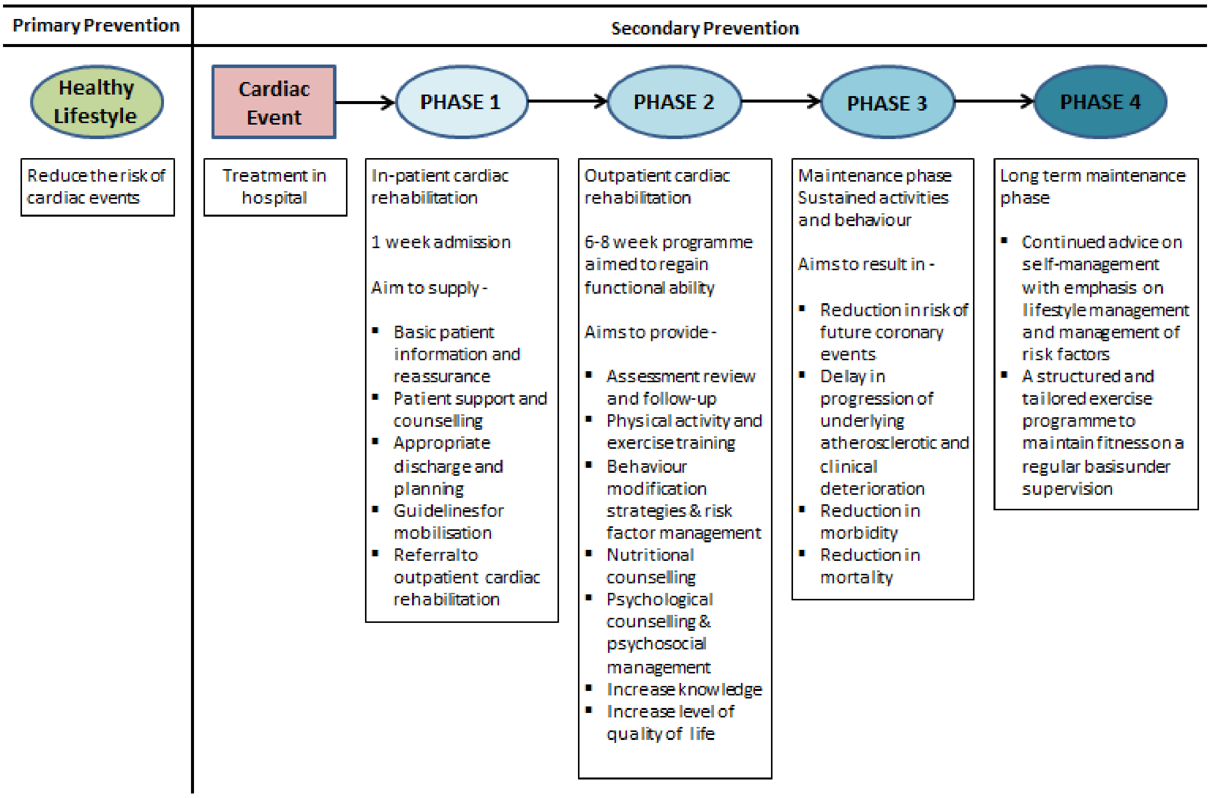
This programme usually started 6-8 weeks after a heart attack or 12 weeks after cardiac surgery or other intervention and lasted for 12 weeks. However, if the patients needed more support then they might remain in phase 3 for longer. Phase 3 took the form of a structured exercise programme with educational and psychological support, and advice on risk factors.

It was tailored to suit individual needs. The CR nurses co-ordinated the programme and the British Association for Cardiac Rehabilitation (BACR) trained fitness instructors to provide the exercise part of the programme.

Phase 4

This phase had two main components. The first was long-term maintenance with advice on lifestyle and risk factors, including management of blood pressure, cholesterol, glucose levels and drug therapy. Secondly, a structured exercise programme in conjunction with the local community was run at local community leisure centres. This was to help encourage patients to maintain their new lifestyle changes, improve fitness, and to promote exercise on a regular basis. Phase 4 was co-ordinated by a CR nurse and the exercise part was led by a BACR fitness instructor.

Below was an illustration of the patient journey, ranging from phases 1-4 (NICE CG48, 2007).



The aim of CR was to help patients recover and get back to as full a life as possible after a cardiac event. It was as much a part of treatment as medicines were. It aimed to give information needed both to look after heart health and to keep well in the future.

CR was offered to patients if the following had occurred:

- Heart attack
- Coronary angioplasty
- Coronary bypass surgery or another type of heart surgery
- Implantable cardioverter defibrillator (ICD) was inserted
- Angina
- Stable HF

While admitted in hospital, a member of the CR team would provide patients with information about their condition and treatment. Advice relating to recovery, lifestyle management and heart health management was provided with a partner or a family member if possible, in these conversations.

A CR team might include a:

- Cardiologist

- Cardiac nurse
- Physiotherapist
- Exercise specialist
- Occupational therapist
- Dietician
- Psychologist

It was likely that patients might not get to see all of the above professionals but might see some of them either while in hospital or afterwards as an outpatient.

Cardiac rehabilitation programmes started after discharge from hospital and were important for everyone, regardless of the duration any patient had stayed in hospital. A CR programme provided the correct level of support and information required for patients to equip themselves with the knowledge they needed to make lifestyle changes. This in turn helped to both reduce and control risk factors. The risk of getting coronary heart disease also depended on other factors, like your sex, age, family history and ethnic background; nothing could be done about these four risk factors. However, much benefit was gained from controlling any other risk factors.

A risk factor was something that increased the chances of getting a disease. Risk factors for coronary heart disease included:

- Smoking
- High blood pressure
- High blood cholesterol
- Physical inactivity
- Obesity
- Co-morbidities such as diabetes

Feelings of anxiety and worry were normal post discharge from hospital but, as time went by, cardiac rehabilitation teams could offer support, especially in the first few weeks. One of the team members might carry out a home visit or telephone patients to check on their progress. Alternatively, a helpline service might be offered which could be accessed for advice and information.

The first few days for everyone were different. It was normal to feel tired and so it was advised to rest for a few days. A supply of medicines was given to take home. Prescribed medicines were important to take as suggested and if any questions about medicines arose, the GP, cardiac rehabilitation team, or pharmacist were signposts for further advice and support.

It was normal to have mixed emotions after being diagnosed with a heart problem. A sense of gratitude and relief may occur as treatment to help improve the heart condition had been given. However, many concerns and worries about further heart problems, or feelings of anger of living with a heart condition might present itself; these were expected as part of the recovery process.

Feelings of anxiety, low mood, bad-temperedness or weepiness might also be part of how one was feeling post diagnosis and treatment. It was important to talk about these feelings with family or friends, the cardiac rehabilitation team, or people at a heart support group. Attendance to a cardiac rehabilitation programme had been shown to reduce anxiety and depression. Additional support, such as counselling, or prescribed medicines if necessary were available from the GP.

Regular physical activity could help with recovery and independence. The amount of physical activity post discharge from hospital would depend on the specifics of the heart condition, the treatment given and recovery process. The cardiac rehabilitation team would help with tailoring a plan that focused on increasing the physical activity level that was suitable for each patient. The cardiac rehabilitation teams would provide support with return to work information and support patients with the knowledge they needed to understand how to equip themselves with tasks they required help with on a daily basis.

Sexual activity presented no greater risk of triggering another cardiac episode than if a patient had never had one. Sexual activity could be resumed as soon as a patient felt they had recovered. For most people this was within a few weeks, but some people preferred to wait longer. Loss of sex drive was not uncommon after illness. Some men might experience impotence (difficulty getting or keeping an erection). This might be the result of emotional stress. Sometimes it could also be the result of taking certain medicines such as beta-blockers, or the result of circulation problems or diabetes. Impotence was a common problem and it was advised that patients sought further advice from their GP and/or the cardiac rehabilitation team about it.

Follow-up appointments were given to patients to visit the cardiologist or surgeon after their stay at hospital. Alternatively, these might happen with the cardiac rehabilitation teams or GP.

The aim of cardiac rehabilitation has been to help with recovery and to help support patients resume as full a life as possible. An invitation to the programme, which started after a hospital stay aimed to provide information, support and confidence to help patients make healthy lifestyle choices. Research showed that cardiac rehabilitation reduced mortality and led to an improvement in quality of life. The programme usually involved going to several sessions, each lasting an hour or two, and either once or twice a week. All programmes varied both in duration of session and in the number of weeks they ran. Programmes were usually run in a hospital, or in a community or leisure centre.

CR programmes and services varied widely throughout the UK. Programmes usually included one or more of the following:

- Physical activity
- Education on healthy lifestyle choices, such as sticking to a healthy diet, managing weight, quitting smoking and how to take medicines including managing related co-morbidities
- Relaxation on how to manage long-term management of the condition
- Psychological support teaching different relaxation techniques in helping to manage stress levels. Some programmes might offer one-to-one counselling or advice on managing stress levels to people who needed it. A psychologist might also be available for additional support.

A cardiac rehabilitation specialist would agree a structured programme of goals and activities that were best for patients and helped educate and support recovery, confidence and general wellbeing in a safe and supported environment.

Other benefits of a cardiac rehabilitation programme included:

- Confidence building, which would aid in supporting the process of returning to usual activities more quickly
- A chance to ask questions or talk about any worries or concerns relieving anxiety
- Meeting other people who had been through the same experience, which was known to be very helpful
- An opportunity for family caregivers to be reassured by the recovery process and give them the chance to ask questions. They might also benefit from talking to other family caregivers.
- Most programmes were happy for a patient to bring a partner, relative or friend to the programme

Monitoring the effects of long-term maintenance was where primary care practitioners were most needed. The issues to be considered included identifying and discussing cardiac misconceptions, giving positive reinforcement to maintain a healthy lifestyle and general screening in a structured manner. Referral and recall systems should have been in place to ensure optimum care was given.

Comprehensive CR programmes tended to provide a range of services to aid the recovery of patients and to support family members in their role as family caregivers. Exercise and education were usually the main components, though coronary risk factor modification and attention to the psychological sequel of coronary heart disease, through counselling, relaxation and stress management techniques were also important. Visram et al (2008) broke down the facilitators of CR into five major themes: group factors, appropriate venue and activity, perceived health benefits, added value and other. They argued that the presence of these facilitators could help to improve CR. Healthcare professionals working in CR had been optimistic about the positive gains that accrued for patients and their family members, in particular partners.

Nurses were ideally placed to co-ordinate and deliver the programme, as they had consistent and continuous contact with the patient and their family members at all stages of recovery, in addition to other health professionals. In a survey, by Thompson & Bowman (1997), 84% of CR programmes in England and Wales were co-ordinated by nurses and 16% by physiotherapists. The majority of these programmes were initiated and developed by nurses, usually of their own volition and in their own time, with few resources and little support. There had been a strong, growing body of evidence to suggest that CR programmes reduced patient morbidity and patients who attended such programmes had significantly fewer hospital readmissions and reinfarctions at 1, 5 and 10 years after the first MI (Bondestam et al, 1995; Hedback & Perk, 1987; Hedbäck et al, 1993).

There were some gender differences in terms of CR. Women tended to differ in their presentations, treatment and outcome of CHD compared to men (Fransoo et al, 2010) and they were more likely to be older (Weaver et al, 2010). Women are also less likely to be referred to CR programmes (Ades et al, 1992) and even when they were, they were less likely to attend than men (McGee & Horgan, 1992). This might be due to the orientation of programmes towards male requirements or due to a tendency to select younger, lower risk patients for CR programmes (Schuster & Waldron, 1991). Visram et al (2008) found that the barriers to CR were more acute for SA women. They categorised the barriers to CR into three major themes: individual, cultural and practical. They argued that if CR programmes could identify these barriers, they would be better able to make adaptations to improve the accessibility of CR programmes for both men and women.

The idea that both men and women required equal access to CR rehabilitation was based on the evidence that attending a CR programme had the same functional benefits for both genders (Lavie & Milani, 1995). On the other hand, elderly people did not gain equal access to CR. This might be due to a shortage of resources, which encouraged selection bias towards younger patients. The bias might be a result of the misconception that older patients were less likely to benefit, and would gain less, from CR than younger patients (Thompson et al, 1997).

In regard to the relationship between CR and ethnic minorities, there was very little evidence. Some studies had tentatively suggested that Indian immigrants are at greater risk of CHD than the White British population (Miller et al, 1998; Balarajan, 1991). This is particularly the case for SA immigrants living in West London, who were found to have a poorer health profile (body mass, blood pressure, blood fats, blood sugar and insulin sensitivity), compared to siblings living in the Indian subcontinent (Bhatnagar et al, 1995). The survival rate following a course of MI for SAs was not clear. Mukhtar & Littler (1994) claimed that there was no difference between SAs and White populations, whereas Wilkinson et al (1996) suggested a higher incidence and death rate for SAs compared to White populations.

The success of CR programmes also depended on financial issues. There had been no comprehensive assessment of the cost of CR in the UK to date, but it was estimated that the total cost of CR in England ranged from £10,000 to £62,000 per year, per centre. This translated into a mean cost per patient of £47 per session, per patient, or £370 per programme (Gray et al, 1997). It was widely accepted that an educational programme was essential if the process of CR was to be successful. This process should be structured, systematic, co-ordinated and appropriate to need. It should start at the time of the cardiac event and continue throughout the course of rehabilitation. The information given to patients during their stay in hospital was often imprecise, with the emphasis often being on one aspect of the multidisciplinary CR process, such as diet (Murray, 1987). As a result, the health education programme should address a wide range of issues in order to enable patients and partners, where appropriate, to make changes to their health behaviour based on knowledge of potential risks and benefits. For patients to have access to this knowledge, there needed to be a range of patient instruction material developed. This might include programmed instruction booklets covering a range of cardiac health topics, which had been shown to significantly improve patient knowledge (Moynihan, 1984).

Orzeck & Staniloff (1987) argued that there needed to be further intervention following hospital discharge because patients commonly forgot the information, they have received during their stay in hospital due to the distress they were feeling at the time. As a result, the period immediately following discharge could be used to further educate the patient and the family. This period would also better enable healthcare professionals to take into account the different beliefs that patients hold in regard to CHD, which must be assessed before delivering the education programme (Fielding, 1991). It was possible that this could be a suitable time for healthcare professionals to take into account religious and cultural factors that might pose challenges for SA patients. Furthermore, Ley (1988) argued that verbal information given during hospital stays should be supplemented by clearly written information. Audio-taped information might also be effective as a means of self-help for those who suffer from anxiety and depression (Lewin et al, 1992).

It was generally agreed that once a patient's acute symptoms had abated, they should return to a programme of physical activity, preferably a home-based one, in order to delay the progress of morbidity and mortality. This would allow patients to reduce their symptoms.

2.4.4 SERVICE PROVISION

The literature identified three main problems with the provision of services for HF patients. The first was regarding interpreters and translation services. There was wide criticism of the role of interpreters and the appropriateness of translated information brochures. Shaw & Ahmed (2004) noticed that many translated texts from English into Urdu retained many of the medical terminologies of the original English text. They argued that a 'direct translation' of technical vocabulary from English into Urdu was inappropriate because the educational level of the native Urdu speakers was lower than that of a typical native English reader. As a result, they recommended a sophisticated and complex translation process in order to quality assure the translation of literature and information brochures from English into minority languages. However, many of these recommendations were based on a limited understanding of how the translation industry worked and were based solely on the needs of one minority ethnic group. Therefore, Shaw & Ahmed's (2004) proposal was not a one-size-fits all solution, which highlighted the complexity of ethnicity and cultural issues in relation to service provision.

The second problem affecting service provision was the cultural barriers that occurred during nurse interventions. Evidence suggested that nursing interventions were beneficial and reduced the number of hospital readmissions (Gerrish et al, 2000; Ortiz et al, 2013.). However, Gerrish et al (2001), and Fleming & Gillibrand (2009) found that often SA women did not feel comfortable with nurses from other cultures because they felt that they did not understand their cultural and religious needs. As a result, nursing interventions had taken into account the cultural and religious sensitivities of the patients in order for it to be fully effective. Furthermore, the fact that SA women felt that they were unable to form a close rapport with their nurse was based on the fact that the two people did not share a common culture or language and therefore it was difficult to relate and form a rapport compared to a White patient with a White nurse, for example.

The third intervention was counselling. Evidence suggested that HF could have profound mental health impacts on the patient and his/her family, partner and/or family caregiver. As a result, counselling was recommended and often put forward as a solution to the dynamic issues that typically appeared after discharge from hospital. However, there were additional challenges with counselling provision for ethnic minority patients, again linking back to language and culture. Since the basis of counselling was a one-to-one relationship, this was difficult to achieve if the patient and counsellor did not share a common language. Similarly, it might be difficult for the counsellor to empathise with the patient if he/she did not understand the patient's culture. A further problem was that counselling was often suggested as a part of the patient's self-care package and so there was no clarification about whether this service was funded by the NHS, or if the family was responsible for funding this.

Finally, Gerrish (2000) argued that it was difficult to expect service providers to make adaptations for ethnic minorities because there were so many discrepancies with the term 'ethnicity' in the first place. The fact that 'ethnicity' and 'culture' have been fluid concepts that were adopted for use meant that the validity of research and critiques of service providers could be questioned. As a result, it was an unreasonable expectation that service providers should make adjustments for 'ethnicity', if 'ethnicity' had not been sufficiently defined.

Mullen et al (2013) looked at inequalities within the pre-hospital environment care stage within minority ethnic groups as opposed to primary or community care to explore the causes and consequences of any differences in delivery. A systematic literature review and narrative synthesis was conducted and from the studies that met the criteria for the review it was found that the main outcome measures were delays in patient calls, mortality rates and 30-days survival post discharge. Most prominent barriers have appeared to show poor communication where English was the patient's second language; new migrants' lack of knowledge of the health care system led to inappropriate emergency calls; and cultural assumptions among clinical staff resulted in inappropriate diagnoses and treatment. It was reported that facilitators would address and improve services which would include the need for translation services and staff education.

Research relating to Asthma further highlighted the aforementioned points. Asthma has been a common chronic condition responsible for significant childhood morbidity with escalated care burden for families, communities and health professionals (Asthma UK, 2009). SA children diagnosed with asthma were less likely to receive prescriptions for reliever medications as compared to White children. Furthermore, children of minority backgrounds endured exaggerated and uncontrolled symptoms with multiple admissions with no evidence to suggest that they had more severe asthma (Netuveli et al, 2005; Kuehni et al, 2007; Asthma

UK, 2007). Understanding the barriers to care, particularly within groups that were most vulnerable was essential in addressing health inequalities. Lakhanpaul et al (2014) undertook an extensive systematic review of studies using multiple data sources containing both mixed methods which identified explanations of both barriers and facilitators that understood to asthma management in SA children (0-18 years), family caregivers and health professionals having involvement of asthma. The following several explanatory factors were identified:

- Lack of asthma knowledge in families and healthcare professionals
- Under-use of preventer medicines
- Denial of asthma
- Over-reliance of medical emergency service management
- Communication barriers
- Non-adherence to medicines
- Alternative uses of complimentary therapies

The authors found very little support for facilitators that aided in asthma management. Key issues were identified that resonated with both ethnic-specific families of South-Asian descent and minority ethnic communities. It was agreed that further research honing in on why barriers exist and the mechanisms by which they impacted asthma management was needed with a view of tailoring appropriate interventions systematically addressed the needs of ethnicity and/or minority communities when understanding better the barriers to the management of asthma.

Further evidence documenting considerable and persistent health inequalities with respect to ethnicity had led to increasing sensitivities to the delivery of health interventions. Members of certain ethnic groups experienced higher rates of obesity, diabetes and cardiovascular disease (CVD) in comparison to White European-origin populations (Sproston & Mindell, 2004; Bhopal, 2009).

Improving access to and participation in health promotion interventions had the potential to reduce the gap of the burden of long-term conditions and reduced ethnic health inequalities (Department of Health, 2010; Scottish Government, 2010). Adaptation of health initiatives could help address the needs and preferences of ethnic minority groups to improve health outcomes and narrow the gap of inequalities (Nielsen & Krasnik, 2010).

Liu et al’s (2015) review of adaptation literature explored the perspectives of health researchers and promoters working on health promotion interventions to reduce smoking, increase physical activity and healthy eating in African, SA and Chinese-origin populations around the world, as these populations accounted for the majority of the diversity documented in many economically developed countries. The authors employed three key concepts, intersectionality, representation and context to underscore how health promoters and practitioners came to understand the lived experience of ethnicity, and how adaptations worked or did not work in light of these experiences.

Intersectionality acknowledged the centrality of factors such as gender, ‘race’, age, ethnicity, religion, class, sexual orientation (Bowleg, 2012). Representation understood ‘the form an object takes and the meanings encoded in that form, such that the meaning isn’t inherent in the object itself but is socially constructed’ (Liu et al, 2015). The authors in their study showed ‘ethnicity’ and its component parts (culture, religion, language, ancestry and physical features) captured real life experiences. Finally, context referred to the experience of space and place through time, which included perceptions of distance and proximity, feelings toward demarcations and boundaries, and attitudes on interactions and relations (Gupta & Ferguson, 1992). Space, therefore, became invested with ‘richly symbolic, aesthetic, moral and importantly, identity-relevant meanings’. A related concept, place, referred to the local, cultural and personal experiences formed through interactions with and within sites, over time (Durrheim & Dixon, 2005).

The intersections of population demographics with ethnicity found significant influences with the way ethnicity became relevant in the intervention. Ethnicity-associated preferences for intervention facilitators were found to interact with gender and age associated preferences. Sensitivity to existing health problems related to age was seen to potentially affect participation in an intervention for a group of African American women in midlife. The SA participants in the UK, ability to participate and partake in physical activity revealed an ethnicity-contingent gendering of seemingly neutral technological aids to exercise, in concordance with varying levels of adherence to traditional dress. Another example of interaction between ethnicity and gender was reported in a smoking cessation intervention, such that, for Chinese participants, gender aided with the termination of smoking through social support. The Chinese population, the men, became smoke free and celebrated this success with their family members so they would not encounter relapse (New Zealand).

The intersections of ethnicity could alter the way people interact, interpret and participate in adapted interventions. Researchers could help to capture the lived experiences in groups of individuals who were distinct by empathy in their commitment to these lived experiences by demonstrating their in-depth knowledge of the pertinent issues through the active development of deep-rooted, complicated double-edged long-term relationships. Adapting health promotion interventions for ethnic minority groups depended greatly on experience, empathy and expertise of health researchers and promoters.

The importance of community engagement and building trusting relationships (Rooney-Browne et al, 2011) was essential in delivering material that built linkages with organisations. Much of the reported thinking in this study echoed the evidence in existing literature, recognising that it was important to be dynamic when describing entrenched and immutable characteristics attributed to persons or groups in healthcare and health research. The authors had shown processes and thinking that underpinned adapted interventions for ethnic minority populations. Mapping these concepts, processes and relationships had both practical applicability and analytical value both for intervention delivery and analysis.

Bhui et al's (2015) study further concurred the importance of culturally adapted therapies that emphasised effective communication between Black and minority ethnic patients and their caregivers and professionals in psychiatric services. The importance of culturally adapted psychotherapies was effective and preferred by patients and family caregivers (Priebe et al, 2011).

2.5 THE ROLE OF FAMILY CAREGIVERS

The terms 'family carer' and 'family caregiver', among other terms, were often used interchangeably to describe the different roles associated with the rehabilitation of a HF patient. The term had been used to describe the healthcare professionals, in particular nurses, as well as family caregivers, in particular the patient's partner. As a result, there have been some major discrepancies within the literature in terms of what the role of the 'caregiver' was in relation to HF, as it was not clear if the caregiver was referring to primary care services staff or to family members. Hupcey et al (2012) made a distinction between 'carer', in the general sense, and 'family carer' to refer specifically to caregivers that were also family members.

The role of the caregiver was central to the effective rehabilitation of HF patients. These caregivers included both primary care staff, such as nurses, as well as family members. However, Hupcey et al (2012) argued that the support of family members as caregivers was the most important and the most essential of all caregiver roles. However, it was often the case that the roles and responsibilities forced on the caregiver had negative impacts on the relationship between the caregiver and the patient and the mental and physical wellbeing of the carer himself (Pattenden et al, 2007; Astin et al, 2008; Bahrami et al, 2014). The impact of the caregiver role on partners and family members had been studied in significant depth and several suggestions had been proposed for the development and improvement of services for carers (Katbamna et al, 2002; Cortis, 2000). The problem at that moment was that the healthcare system relied on carers to take over the responsibility of primary care staff once the patient had been discharged. Despite a turn towards a discourse of 'self-care'

(Saunders, 2008), it was likely that the role of the family caregiver was significantly underestimated and underappreciated. As a result, while there were service provisions for the patient himself, there were few services for the caregiver, even though studies had found that caregivers suffered from high rates of stress, anxiety and depression. In addition to these negative mental health impacts, family caregivers often found that the dynamics, behaviours and the intimacy of the family had changed. Some studies had advised that families seek counselling to support them through this change (Pattenden et al, 2005), but this was not always possible. The irony, therefore, was that the measures taken to improve the health of the patient could be to the detriment of the health of others, and this was due to a healthcare system dependent on self-care and family caregiver support.

Katbamna et al (2001) argued that the challenges and barriers for SA carers were more significant than those faced by the majority White population. This might be due to factors relating to typical power imbalances between majority and minority groups, such as lower socio-economic background and cultural and linguistic differences. However, one of the most important findings from the study by Katbamna et al (2001) was that there was evidence of implicit racism from GPs towards male SA carers in particular. They also argued that a SA GP did not improve the situation either – in fact it often exacerbated it. The reason for this was down to cultural expectations. The belief that it was the family’s moral duty to look after a disabled relative within SA culture fuelled the expectation on SA family caregivers to put aside their own health concerns for the sake of the disabled relative.

On the one hand, this belief reinforced the importance of the role of ‘family caregivers’ and perhaps even reduced discord within the family dynamic, since it was simply expected that the family would care for the disabled relative. This was in contrast to White families, where family caregivers tended to be more vocal about the pressures and stresses associated with being a family caregiver. On the other hand, the belief that the family caregiver’s own health should come second could only be detrimental to the relative’s rehabilitation process, since if the family caregiver became ill from the pressures and stress of being a family caregiver, the rehabilitation of the relative was certain to be affected negatively.

These spiritual and moral beliefs typically held among SAs affected their access to services because if they believed that they were responsible for bearing the stress and pressure of rehabilitation, there was no requirement to seek support. These discordances between culture and belief systems were identified by Katbamna et al (2002), who also made the point that often family caregivers were unable to access services not because of cultural barriers, but simply because the services did not take into account their needs.

Cortis (2000b) covered some of the same issues but focused primarily on the idea that the primary reason that SA family caregivers had poor access to services was due to cultural issues. He argued that these ‘cultural’ issues might not have any relation to ethnicity or language. He referred to the concept of ‘inter-cultural communication’ from a more abstract perspective, arguing that communication across gender, social class, ethnicity and language all constituted instances of ‘inter-cultural communication’. From this perspective, therefore, Cortis (2000b) criticised the healthcare system based on its inability to adopt a wide range of communication skills to meet the needs of all cross-sections of society. He concluded by arguing that issues of culture are not yet sufficiently embedded in nursing education, resulting in these cross-cultural miscommunications.

The role of family caregivers, therefore, was a complex one that drew into issues of culture, ethnicity, social class and language. Differences in belief systems among different minority groups was likely to affect the way that family care was provided and also the ability of that group to access services. As a result, healthcare services and primary services for HF must take into account the complexity of the role of caregivers and try to find solutions. One solution could be reducing the dependency on self-care and family care.

There were several implications for the patient’s family member or partner, following discharge from hospital. The family caregiver was likely to have additional domestic responsibility, which might potentially lead to a similar level of social disability as the patient (Mayou et al, 1978). The added pressures and responsibilities on the family caregiver typically led to tensions and contentions, arising from the fear that the coronary incidence may reoccur (Skelton & Dominion, 1973). These pressures could also come in the form of financial difficulties and a lower standard of living, which might adversely affect recovery (Bennett, 1992). Often, patients and their carers chose to receive counselling for emotional support and to help them change their behaviour. The benefits of counselling were rarely immediate, but after a sufficient duration it could help individuals to regain a sense of control (Thompson et al, 1999). Similarly, maintaining contact with a nurse in the period immediately following discharge from hospital could reduce depression and increase the patient’s sense of his/her quality of life (Unden et al, 1993).

Further research with SA caregivers had supported the argument within the area of stroke where the role of the caregivers had placed much demand on physical, emotional and social well-being (Anderson et al, 1995). This had led to a renewed interest in understanding their needs and concerns in order to provide appropriate support (Mant et al, 2004). Savita et al (2017) explored qualitatively White and British Indian informal stroke carers’ experiences of caring, factors contributing to their stress, and strategies used to overcome stress at one and three to six months from the onset of stroke. The authors found that irrespective of ethnicity and gender, the carers' emotional and physical well-being was undermined by the uncertainty and unpredictability of caring for stroke survivors and meeting their expectations and needs (Greenwood et al, 2009). The strain of managing social obligations to care was common to all carers as a majority felt overwhelmed and ill-equipped. High levels of anxiety and depression were reported by Indian British female carers (Katbamna et al, 2004). These appeared to stem from the carers' pre-existing physical ailments, their cultural and religious beliefs, and household arrangements. Carers' strain in extended households was exacerbated by the additional responsibility of caring for other dependent relatives. The role of carers was indispensable in the successful rehabilitation of survivors; it was vital to ensure that their well-being was not undermined by a lack of information and training, and that their need for professional support was prioritised.

2.6 CONCLUSION

Living with HF has been a complex, dynamic process for both patients and family caregivers. It involved multiple challenges including coping with frightening symptoms and complex medications, depression and anxiety, a loss of role and functional abilities resulting in a poor quality of life (Stewart et al, 2001). It was evident from the literature that the incidence of HF was increasing in the UK and there was growing concern about the health, social and psychological needs of people experiencing advanced HF (Cowie et al, 1997a; Murray et al, 2002). The total number of patients suffering from HF in the UK was estimated to be between 800,000 (National HF Audit, 2013) and 900,000 (NHS, 2015; NICE, 2010).

SA individuals living in the UK had higher cardiovascular mortality and morbidity compared to the White population. SAs had a 50% greater risk of dying prematurely from CHD. Furthermore, the difference in death rates amongst HF patients was greater for SA than the rest of the population as the death rate from CHD was not decreasing amongst SA patients as it was with the rest of the White population (Myers et al, 2009). Due to its susceptibility, congenital heart disease (CHD), hypertension, multiple myocardial infarctions and diabetes acted as the leading causes of HF in SAs.

The literature related to culture, ethnicity, language and religion in relation to HF was limited and often ethnic background was not reported. Minority ethnic groups were less likely to have the knowledge and understanding of how to access and seek appropriate medical advice and healthcare which could improve their quality of life, health, wellbeing and decrease the risk of morbidity and mortality. People from ethnic minority backgrounds were often educationally and economically disadvantaged, resulting in them being less able to gain access to educational materials (Johnson et al, 2006b).

Thus, the inclusions of the Pakistani community and its community’s needs in the UK had been neglected as a separate entity as it had been paired with SA groups or otherwise. A demand, therefore, for further research to explore the needs of the Pakistani community specifically was essential if wider understandings of the components amalgamating the Pakistani community in the UK were to be understood. Addressing Islam, the Pakistani culture together with lifestyle risk factors would expand the understanding of tensions that the Pakistani community faced which hindered help-seeking provision that was important in the assistance of treatment and rehabilitation both clinical and in non-clinical form. Treatment including medicine adherence, quality of life, language barriers, knowledge and education for patients and their caregivers must be addressed (Hupcey et al, 2012). It was vital to ensure that well-being was not undermined by a lack of information and training, and that professional support was prioritised. The aim of CR was to help patients recover and get back to as full a life as possible after a cardiac event. It was as much a part of treatment as the medicines. Cardiac rehabilitation aimed to give information needed both to look after heart health and to keep well in the future.

In conclusion, there were three major themes that stood out in the literature: linguistic barriers, cultural barriers and attitudes towards self-care management and rehabilitation.

There was as much a part of treatment as medicines were a significant cross-gender difference in terms of linguistic barriers where women were at a significant disadvantage compared to men. The language barrier also appeared to be much stronger for older people. The language barrier and poor access to interpreting services, which forced SA patients to rely on family members, created major difficulties especially where medication was as much a part of treatment as medicines are concerned. Many patients did not understand why they needed to take their medication and therefore they were forced to trust family members and healthcare professionals. This lack of functional English could lead to patients relying on family members or trained interpreters.

Finally, the evidence hinted at the possibility that healthcare professionals themselves were the root cause of many of the challenges SA patients faced because they did not understand or take into account the linguistic and cultural barriers. This difference in perspective and lack of understanding from both healthcare professionals and the patient, resulted in a culture clash, reducing the efficiency of healthcare services. There were also gender-specific problems, namely that it was problematic for SA women to be treated by a male doctor. The same issue was also true when it came to attitudes towards self-care and rehabilitation management; it was culturally inappropriate for SA women to attend mixed-sex exercise classes, which posed problems for their CR. Similarly, SA women often had problems with mobility and family responsibilities and so might find it difficult attending CR venues. The main barriers for self-care included diet, exercise, and relationships with healthcare professionals and unreasonable expectations from family caregivers (arising from a lack of understanding of cultural issues).

The importance of understanding the specific needs of Pakistani HF patients and their family caregivers would interject the necessity of how best to tackle this population's needs situating the inclusion of cultural appropriateness and adaptation of ethnic factors that drives health service provision efficacy. A grounded-theory methodology was adopted which allowed the understanding of a phenomenon from the participant's point of view (Baker et al, 1992). Grounded theory 'is most suited to efforts to understand the process by which actors construct meaning out of intersubjective experience' (Suddaby, 2006, p.634). The grounded theory methodology developed, verified, and used inductively through a systematic data collection and analysis built a theory that emerged from the data, facilitating, creating meaning and understanding, addressing and underpinning the needs of the Pakistani HF population and its family caregivers (Strauss & Corbin, 1998). This was directly in line with this study's aims, which have been discussed further in the next chapter.

3 CHAPTER THREE: METHODOLOGY CHAPTER

3.1 INTRODUCTION

This chapter is split into two sections. The first half of the chapter describes the research methodology and demonstrates how the selected research methodology was implemented. The rationale for using qualitative methodology, and more importantly the choice of grounded theory methodology is also presented. The origin of grounded theory is detailed, in addition to a description of the grounded theory method and its application to the study.

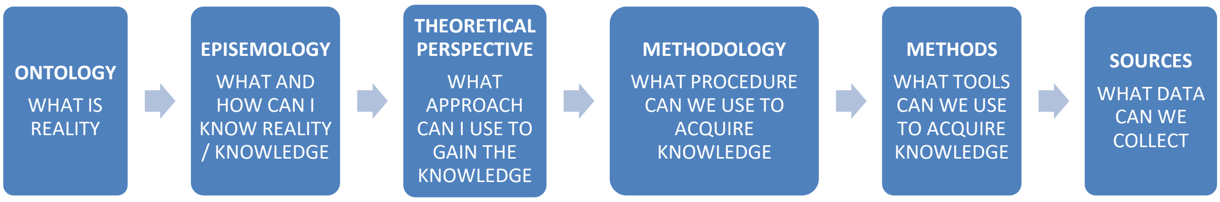
The second half of the study discusses an overview of the sampling frame including the recruitment strategy. The chapter then moves on to discuss the methods of data generation and analysis. Attention is also given to the strategies used by the researcher to maximise methodological rigour in the study. Furthermore, the chapter covers ethical considerations inherent to this study, a description of the heart failure patients as well as data collection and storage methods. Moreover, the procedures undertaken to ensure the trustworthiness, credibility, and transferability of the findings are presented. The chapter concludes with an overview of the study's major findings.

3.2 ONTOLOGY AND EPISTEMOLOGY

The exploration of a research methodology begins with an exploration of the research paradigm and the justification of the selection of approach. A research paradigm is 'the set of common beliefs and agreements shared between scientists about how problems should be understood and addressed' (Kuhn, 1962).

To appreciate my approach in this thesis, I shall outline an understanding of the epistemology, 'how do you know about the reality and what is the basis for this knowledge?' and the ontology which refers to the study of being, 'what is the reality?'

The diagram below explains the above terms and the relationship between them:



(Hay, 2000; Crotty, 1998)

Ontology and epistemology create a holistic view of how knowledge has been viewed and how we can see ourselves in relation to this knowledge, and the methodological strategies we use to discover it. Awareness of philosophical assumptions increases the quality of research and can contribute to the creativity of the researcher. Social science research primarily has sat with:

Experimental (Positivist), a realistic ontology (a reality is out there), with empiricist epistemology (gather data to support this).

Postmodernist constructivism, with a less realist ontology (reality lies within multiple competing claims), and a constructivist epistemology (analyse multiple competing accounts to explore this).

Applied then, to social sciences, it has been important to understand the tension throughout its history, between:

A more traditional experimental approach (quantitative), which saw social reality existing independently of human conceptions and interpretations as a set of facts to be known for all time by measuring people in the laboratory;

A more critical, discursive (qualitative) approach that was context-specific, which saw social reality as mutually constructed between people in the real world.

Pragmatism (mixed methods research) has also being increasingly used in social sciences.

The three most common research paradigms research can belong to were:

Positivists: Positivism has always been closely associated with physical and natural sciences, since the eighteenth and nineteenth century. It has always been prominent in natural sciences. It carried with it the notion that the only valid form of knowledge was that discovered by scientific research (Playle, 1995). The belief that there was a single reality which could be measured, and it was objective. This positivist approach (Erklären) adopted a research paradigm that viewed a reality known as ontology. This objective ontology was likely to use statistical theory testing quantitative methods such as questionnaires that sought to fill the knowledge gap and adopted observable facts to measure a reality and problem solve; it was a natural science which proposed and tested a hypothesis of an X and Y relationship. These disciplines (including epidemiology, social medicine, and sociology) placed a lot of significance on quantification and measurements (Haase & Myers, 1988). The research paradigm adopted the following structure:

- Literature review (this was carried out to fill the knowledge gap)

- Develop model
- Collect data
- Analyse
- Write up

There have been many advantages that exist of positivism. It allowed large amounts of economical collection of data, in addition to a clear theoretical focus for the research from the outset allowing the researcher to retain control of the research process whilst gaining an understanding of social processes and comparable data (Hughes & Sharrock, 1997).

However, the approach was not without its disadvantages. It was very inflexible, lacking in multiple directions that often could not be changed once data collection had started. Furthermore, data collection could be time consuming and weak at understanding social processes making data analysis challenging and complex when failing to adequately discover the meanings people attached to social phenomena's. Moreover, the researcher had to live with the uncertainty that clear patterns may not emerge (Pawson, 1996).

Constructivists: The belief that there was no single reality or truth, the reality needed to be interpreted, and therefore the use of qualitative methods aimed to understand the multiple realities. Interpretivist epistemology viewed no single reality; its aims were to understand multiple realities using qualitative interviews. It was culturally and historically situated in interpretations of meanings, motivations and values of social actors, structures and patterns. It accepted that the truth is out there but was complex and was interpreted through individual meaning, actions and understanding (Verstehen). The epistemology looked at the how/why and the theory of knowledge and how knowledge was obtained. This approach was theory building and adopted the following structure:

- Introduction
- Research aims/objectives
- Literature review (this might be carried out to avoid re-inventing similar research and repetition)
- Research methodology
- Collection of data
- Validating data
- Saturation (on-going data collection/interviewing)

Pragmatists: The belief that reality was constantly re-negotiated, debated, interpreted, and therefore the best method to use was the one that solved the problem.

A description of my research paradigm would be discussed in detail, in addition to which method, methodology, theoretical perspective from which I would approach my research.

In seeking an understanding of these experiences, the researcher recognised the limitations of the positivist approach especially since the understanding of risk factors (related to heart failure and CHD) was relative to individuals and their contexts: there would be differences in thoughts, feelings, behaviours, practices and level of fulfilment. The positivist approach could not encompass this variety of findings as it could not provide any explanation for, nor have an understanding of, the heart failure patients' experiences. Furthermore, another limitation in using the positivist approach was the inability to quantify feelings such as anxiety and satisfaction that did not form objective data. Humans have not always been objective, and their behaviour, feelings, perceptions and attitudes were subject to many influences that positivist research would reject or fail to measure.

By the means of constructivism, the impact of my chosen paradigm would provide ontological insights and understand the beliefs, experiences and the culture (the historical and cultural contexts) to recognise that heart failure patients do not merely view the world differently, but also have experienced it differently. Individuals make sense of events and ascribe meaning to them and bring their uniqueness to their lived experience. The ontology of multiple realities would explore an epistemology within the interpretivist approach that would explore the interpretation of experiences from both the patients' and their family caregivers' perspectives living with heart failure within the Pakistani community. Applied then to grounded theory methodology, eliciting such data through qualitative interviews, would aid the extraction of an emerging theory that would blend perfectly within the aims of the study and philosophy.

3.3 QUALITATIVE RESEARCH

Qualitative research was not new to social or behavioural sciences. Qualitative research has embodied numerous methodological approaches that focus on describing the in-depth experiences of people's lives and the social contexts that strengthen, support, or diminish those experiences (Leininger, 1985a; Munhall, 1989). Qualitative research has provided the researcher with multiple choices and means to explore the depth, richness, and complexity inherent in the phenomena being studied (Carr, 1994). Each methodological approach had a different philosophical stance that guided the questions asked and the procedure used for data collection and analysis. According to Morse (1999):

'they offer alternatives in analytic approaches; cater to different disciplinary perspectives, assumptions, and agendas; provide a means to explore various levels of analysis, from micro-analytic to complex behaviours; [sic] and permit the development of the necessary level of conceptualization [sic] of results' (p. 393).

Although the terminology and the procedures used are determined by the philosophical orientation of the identified approach, for example, phenomenology, grounded theory, or ethnography, there are two major commonalities of all qualitative methodologies (Boyd & Munhall, 1993). Firstly, all approaches have acknowledged that reality changes over time and is based on the individual's perception, making reality different for each person. Secondly, an individual's knowledge only had meaning within a given situation or context and, as each individual's perception differed, many distinct meanings were possible.

The outcomes of qualitative research demonstrated new understandings of a phenomenon, which, when applied more broadly, provided new guides and further theory development. Qualitative research, like quantitative research, followed a pre-determined methodological process. Initially, the researcher identified a problem, provided justification for the merit of the study, determined the study design and selected the participants in qualitative research and/or other data sources, gathered data, analysed and interpreted data, and provided a written report of the results.

The most common data collection methods used in qualitative methodologies included observation, interviewing, and the examination of written text (Silverman, 1993). Grounded theory methodology was chosen for this study because it was viewed as the most appropriate methodology, for ontological and epistemological reasons, for exploring the phenomenon under study.

3.4 THE GROUNDED THEORY METHOD

Sociologists Barney Glaser (1930; Morrow) and Anselm Strauss (1916-1996; Clarke, 2007) developed grounded theory methodology in 1967 at the University of California, San Francisco. Their original grounded theory research was a study on dying and resulted in two texts, 'Awareness of Dying' (Glaser & Strauss, 1965) and 'Time for Dying' (Glaser & Strauss, 1968). The research also led to the publication of a book outlining the methodology used in the study, 'The Discovery of Grounded Theory' (Glaser & Strauss, 1967). At that time, Glaser and Strauss's (1967) work was viewed as revolutionary because:

it challenged (a) arbitrary divisions between theory and research, (b) views of qualitative research as primarily a precursor to more 'rigorous' quantitative methods, (c) claims that the quest for rigor [sic] made qualitative research illegitimate, (d) beliefs that qualitative methods are impressionistic and unsystematic, (e) separation of data collection and analysis, and (f) assumptions that qualitative research could produce only descriptive case studies rather than theory development (Charmaz, 2000, p.511).

Grounded theory is a qualitative research strategy that used a systematic set of procedures to conduct, analyse and theorise a phenomenon under investigation. The purpose of grounded theory was to build a theory that faithfully illuminated the area under investigation (Strauss & Corbin 1990). Grounded theory as developed by two sociologists, Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967) with equal attribution, offered both an approach and a method to data collection and analysis. Furthermore, it facilitated both a micro and macro approach to the data (Strauss & Corbin, 1998). The combination of these approaches allowed the researcher to maintain an interdisciplinary approach to the project. As a methodology, grounded theory sought to generate theory that had its roots firmly in the data that had been collected.

Grounded theory aimed to develop a theoretical framework systematically from the data collected using an iterative spiralling process in which data collection and analysis interacted (Glaser & Strauss, 1967). Hood (2010a/b) suggested five distinguishing features of grounded theory. These were: identification of a broad research area with progressive focussing, simultaneous data collection and data analysis, constant comparison, theoretical sampling and saturation of categories. Grounded theory allowed the researcher to understand a phenomenon from the participant's point of view (Baker et al, 1992). Suddaby (2006) suggested grounded theory 'is most suited to efforts to understand the process by which actors construct meaning out of intersubjective experience' (p.634). Grounded theory provided the researcher with the tools to understand and explain phenomena. This was directly in line with the aim of the study which was to gain insight into the lived reality of heart failure patients living and self-managing heart failure.

Grounded theory was both a methodology and a method that was applied to my study. Grounded theory would gauge with the lived reality of the Pakistani heart failure patients self-managing heart failure and attempted to understand the experiences and journeys that would aid in explaining the processes by which meaning was given to these specific populations' needs. A grounded theory was one that was inductively derived from the study of the phenomena it represented (Strauss & Corbin, 2008) producing an abstract analytical schema that could be applied to a phenomenon in a particular situation (Creswell, 1998). The theory was discovered, developed and verified inductively through systematic data collection and analysis of data pertaining to a phenomenon so that the building of a theory emerged from the data, facilitating, creating meaning and understanding (Strauss & Corbin, 1998).

According to Creswell (2009), grounded theory is ‘a qualitative strategy of inquiry in which the researcher derives a general, abstract theory of process, action, or interaction grounded in the views of participants in a study’ (p. 13 & p. 229). This process involved using multiple stages of data collection and the refinement and interrelationships of categories of information (Charmaz, 2006; Strauss & Corbin, 1990, 1998).

The value of grounded theory was in its ability to examine relationships and behaviour within a phenomenon from an unbiased in-depth perspective. That was to say, when a researcher entered a study with no framework or theory, they were wishing to fit the data into, the doors were open to discovering explanations that had yet to be articulated. More importantly, the explanations ultimately came from the participants that were being studied. When a grounded theory study was executed correctly and rigorously, there was little chance that the resulting explanations had become distorted by the researcher’s personal world view. The time and detailed analysis required to properly execute grounded theory methodology made its use daunting and limited. There were many variables that had to be in place (i.e. resources, experience of researcher, and acceptance of methodological processes) in order for grounded theory to be successfully carried out. When this occurred, the results would be invaluable to the understanding of social phenomena.

In 1990 Anselm Strauss and Juliet Corbin co-wrote the first edition of ‘Basics of Qualitative Research’ which was designed to help the novice researcher (Strauss & Corbin, 1998). The authors presented their understanding of grounded theory in a clear, systematic and practical manner. In ‘Basics’ they presented analytical tools the researcher could use; they broke down the coding process into three key stages: open, axial and selective coding. Strauss and Corbin offered the researcher a way of thinking about the analysis. There was a clear criterion for selecting the core category, the guidance on using memos and diagrams and the chapter on writing theses. Thus, the clear and structured approach to grounded theory for their work offered much hope and sequence to the novice grasping grounded theory in their study. In contrast, Glaser’s (1978b) eighteen coding families have been described as ‘vague’ (Walker & Myrick, 2006) and ‘a hotchpotch of concepts’ (Kelle, 2005, paragraph 14) suggesting the coding families proposed by Glaser could be difficult for novices to grasp. The coding paradigm offered by Strauss and Corbin (1998) was therefore considerably more attractive for the novice to grasp though also not without its critics, most notably Glaser (1992).

A further figure in the field has been Kathy Charmaz, herself a student of Glaser and Strauss (Mills et al, 2006). She advanced the grounded theory field by proposing constructivist grounded theory. Charmaz (2000) stated ‘grounded theorists need not subscribe to positivist or objectivist assumptions’ (p. 511) and she offered a middle ground approach between postmodernism and positivism. Charmaz suggested constructivist grounded theory distinguishes between truth and reality, moving away from a universal truth and representing the reality of the participant. One created a picture of reality rather than reality itself, a point Glaser (2002) directly criticised on the basis that the participant's voice was lost in the interpretation of the researcher.

Strauss and Corbin (1998) offered a structured method, which was adopted in this research, a benefit highlighted by others (Kelle, 2005; Kendall, 1999). A grounded theory (GT) methodology (Strauss & Corbin, 1998) had been selected which had its roots in symbolic interactionism (SI) (Mead, 1934). These disciplines were concerned with the importance of social interactions in interpreting meaning (Blumer, 1971). Individuals developed their own personal meanings about situations and objects by transacting with others (Guba & Lincoln, 1989). At times, every day common sense meanings were developed within specific social groups. However social circumstances were not fixed, and people modified their interpretation based on on-going experiences and evolving situations. There could be no central, unchanging reality and knowledge could never be complete. If a study was grounded in the experiences of participants it could offer some authenticity (Locke, 2001). Grounded theory acknowledged these beliefs and set out to make visible participants' interpretations of themselves in particular social roles and situations (Bryant & Charmaz, 2010).

Symbolic interactionism, a term coined by Herbert Blumer (1900-1987) in 1937, has been an approach in sociology which focused on the interaction of human beings and roles which they had. The model of the person in symbolic interactionism was active and creative rather than passive. Symbolic interactionists perceived human behaviour as essentially social behaviours constituted of social acts. The essence of society lay in joint action. Mead (1934) saw the self as a social rather than a psychological phenomenon. Individuals responded to others and grasped their meanings through forms of communication such as language, gestures and facial expressions. By interpreting and defining each other's language and actions, they chose from an infinite variety of social roles. Members of society affected the development of a person's social self by their expectations and influence. Initially, individuals modelled their roles on the important people in their lives, 'significant others'; they learnt to act according to others' expectations, thereby shaping their own behaviour. Eventually, the individual was able to take on a number of social roles simultaneously and could organise the roles taken from the society, group or community, the 'generalised other'. Mead compared this to team games, where members of a team anticipated the behaviour of other players and could therefore play their own roles (Holloway, 1997).

Denzin (1989) linked symbolic interactionism to naturalistic, qualitative research methods by stating that researchers must enter the world of interactive human beings to understand them. By doing this, they saw the situation from the perspective of the participants rather than their own. This perspective could be uncovered by interviews, observations and diaries. Qualitative methods suited the theoretical assumptions of symbolic interactionism. People could be observed in the process of their work and their negotiations with others. Symbolic interactionism, a distinct theoretical perspective in social psychology that focuses on the meaning of events to people in their natural setting, underpinned grounded theory methodology (Chenitz & Swanson, 1986). The discipline of symbolic interactionism arose out of the Chicago School of Sociology between 1920 and 1950 where George Herbert Mead (1863-1931) used this approach to study human behaviour (Robrecht, 1995). Herbert Blumer (1900-1987; Morrione, 1988), another sociologist, articulated three basic premises based on Mead's (1937) understanding of social Psychology relating to the symbolic interactionist approach (Becker, 1993). According to Blumer (1969):

'human beings act towards things on the basis of the meaning that the things have for them; the meaning of such things is derived from or arises out of the social interaction that one has with one's fellows; and meanings are handled in, and modified through, an interpretive process and by the person dealing with the things he encounters' (Blumer, 1969, p. 2).

Blumer's (1969) beliefs about symbolic interactionism were supported by Denzin's (1989) work that also outlined three fundamental assumptions linked to symbolic interactionism: 1) individuals defined their own situation, 2) individuals were capable of self-reflection, while at the same time directing their behaviour and that of others, and 3) in directing their own behaviour, individuals could interact with others and adjust their behaviour as necessary. In addition, Denzin (1989) linked symbolic interaction to qualitative research and suggested that researchers must enter the participant's world of social interaction to 'fully' allow them to understand the participant's perspective of the situation under study. Streubert and Carpenter (1995) further supported this notion claiming that through social interaction individuals could 'learn about' and 'define' their experiences (p. 260).

Grounded theory had its origins in symbolic interactionism, taking the perspective that reality was negotiated between people, always changing and constantly evolving (Blumer, 1969 & 1986). The research question in grounded theory reflected this interest in process and changed over time, and the methods of making and analysing data reflected a commitment to understanding the ways in which reality was socially constructed. It was these processes of change and social construction that the researcher examined, identifying stages and phases. The assumption was that through detailed exploration, the researcher could construct theory in being grounded in data (Richards & Morse, 2007).

Therefore, through the process of interviewing heart failure patients and family caregivers of heart failure, this study has generated data that could be examined and, through the use of grounded theory, could be explained within an emerging theoretical framework.

It was likely that such theory would be small scale and focused, and techniques would emphasize the ‘continuous interplay between analysis and data collection’ (Strauss & Corbin, 1994, p. 273) until a theory fitting the data was created. The process involved a data-driven design (theoretical sampling). The key goal was the creation of new theoretical concepts from the data and the seeking of core concepts (Strauss, 1987), or the pursuit of what Glaser (1978b) termed the basic social process (BSP) or the basic social psychological process (BSPP) (Morse & Richards, 2007).

Grounded theory studies began to address studies with questions about ‘what’s going on here?’ This was an appropriate method for the researcher wishing to learn from the participants how to understand a process or situation. The questions themselves suggested the examination of a process. Thus, grounded theory was most often situated in experiences in which change was expected, and the method was becoming commonly used in research as it aimed to understand change and processes that were central to health studies. An example to illustrate this point was put forward by Morse and Bottorff (1988/1992; Olson, 1985) who studied mothers who were breast feeding. In particular, they were interested in breast milk expression. They asked: ‘what are the perceptions of mothers who express? What are the feelings and attitudes that are evoked by expressing? How do mothers learn to express?’ (pp. 320-321).

Grounded theory is derived from the study of the phenomenon it represented (Glaser & Strauss, 1967). Two types of theories, substantive and formal, could be produced using grounded theory methodology (Backman & Kyngäs, 1999). Substantive theories concentrated on a specific social process and were developed for a narrower empirical area of study. Substantive theories could be used to generate or re-formulate existing formal theories (Blaikie, 1993). Substantive theories were relevant to the people concerned and were readily modifiable (Glaser, 1978a). In contrast, formal theories were more general and dealt with a conceptual area of inquiry (Strauss & Corbin, 1990; Morse & Johnson, 1991) that could be related to a range of substantive areas (Blaikie, 1993). Both substantive and formal theories were mid-range theories, and while narrower in scope than grand theories, provided valuable insights of reality and were useful in linking theory with practice (Fawcett et al, 1995).

Glaser and Strauss (1967) alleged that theories were deducted from logical assumptions or generated through observation. Their basic position regarding grounded theory was that it was a 'way of arriving at theory suited to its supposed uses' (p. 3). Grounded theory was an inductive approach that derived its name from the practice of generating theory from observational research that was 'grounded' in data (Babchuk, 1997). The goal of grounded theory was the construction of theory that gave understanding to the phenomena being studied. The finished theory should be 'inductively derived from data, subjected to theoretical elaboration and judged as adequate to its domain with respect to a number of evaluative criteria' (Haig, 1995, p. 1). According to Charmaz (2000)

'the power of grounded theory lies in its tools for understanding empirical worlds' (p. 510).

The methodology enabled the researcher to generate explanatory theory about social and psychological phenomena rather than generating results to support or test existing theories (Glaser & Strauss, 1967).

The resulting theory was an explanation of categories, their properties, and the relationships between them (Calloway & Knap, 1995) and it was a powerful way of interpreting reality (Strauss & Corbin, 1990). Theories based on data could not be refuted or replaced by another theory and since it was linked to data it was destined to withstand inevitable modification and reformulation (Glaser & Strauss, 1967). Chenitz and Swanson (1986) stated that:

The objective of grounded theory is the development of theory that explains basic patterns common in social life. Grounded theory represents an advance in technology for handling qualitative data gathered in the natural, everyday world. It describes a method to study fundamental patterns known as basic social-psychological processes which account for variation in interaction around a phenomenon or problem (p. 3).

As with any research technique, grounded theory has strengths and weaknesses. The main criticism of grounded theory was that the epistemological assumptions were not clearly explained (Charmaz, 1990). Weaknesses in the use of grounded theory had mainly been attributed to the researcher not fully understanding grounded theory methodology, not using the constant comparative method of data analysis throughout the study, and threats to the researcher's theoretical sensitivity, for example, due to over familiarity with the study area (Backman & Kyngäs, 1999; Wilson & Hutchinson, 1996).

3.5 APPLICATION OF GROUNDED THEORY FOR THIS STUDY

Qualitative research has diverse techniques and philosophies. When considering the overall aims of my study, many approaches were considered. The three approaches of Phenomenology, grounded theory and ethnography were all potentially suitable approaches relevant to this study. The three approaches shared many similarities when providing descriptions of situations and personal experiences. All three strategies offered a means of exploring the understanding of the experiences of Pakistani heart failure patients and their family caregivers living with heart failure. However, whilst these methods had the opportunity to provide valuable insights, phenomenology and ethnography were rejected. I will briefly discuss and provide a rationale for this.

Phenomenology came from the academic disciplines of philosophy and psychology, and it was based upon the work of the 20th century philosopher Edmund Husserl, which was then later developed by Heidegger. Phenomenology aimed to understand the 'constructs' people use in everyday life to make sense of their world and uncover meanings contained within conversation or text. Phenomenology gathered lived experience descriptions rather than opinions, views, beliefs and interpretations. Thus, direct descriptions (depictions, renderings, portrayals) of an experience as lived through in a particular moment of time. This methodology was not appropriate as it did not address the aims and outcomes of usability and applicability for my study in the healthcare field. Though phenomenology would illuminate and clarify central and important issues, it would not further the applicability of findings to the development of an emergent theory of social actions leading to the identification of analytical categories and the relationships between them to identify the needs of the Pakistani population and healthcare professionals. Therefore, Phenomenology methodology was rejected.

Ethnography, an anthropological disciple which aimed to understand the social world of people being studied through the immersion in their community to produce detailed description of people, their culture, traditions and beliefs was also rejected as time limitation would not permit under-going such an extensive study. Furthermore, I was neither skilled nor experienced to carry out a fair, representative or accurate role which would address the immersion and long-term 'live and work' approach.

While I was aware of the continuing debate concerning grounded theory methodology, I believed it was appropriate to continue to use this approach in the pursuit of producing a substantive theory of patient and family caregiver experiences managing chronic heart failure which would impinge on the relevance and application to self-managing heart failure within the Pakistani community.

Grounded theory methodology provided a sound procedural method to study the research phenomenon and, therefore, triangulation with the use of quantitative methodology was not employed in this study. Morse (1999) also supported this notion and made a plea for methodological pluralism - not the ad hoc mixing and matching or the blind methodological muddling of strategies or methods, but consideration for the multiple ways in which one problem or one context might be explored – and the awareness and respect for the alternative ways in which research could possibly proceed. The researcher argued that different research methods answer different research questions and used different research perspectives and different types of data according to the question asked (Morse, 1999, p. 393).

3.6 SAMPLE

Men and women of Pakistani origin were invited to participate in this study. A New York Heart Association Functional Classification (NYHA) of 1, 2 and 3 was included adopting:

Class 1: no limitation was experienced in any activities; there were no symptoms from ordinary activities.

Class II: slight, mild limitation of activity; the patient was comfortable at rest or with mild exertion.

Class III: marked limitation of any activity; the patient was comfortable only at rest.

An NYHA of 4 was excluded. A NYHA classification of 1, 2 and 3 presented heart failure patients that access rehabilitation services and who were put forward for rehabilitation whereas NYHA 4 highlighted heart failure patients' inability to be included in rehabilitation, thus excluded from participation.

This score documented severity of symptoms and was used to assess response to treatment. While its use was widespread, the NYHA score was not very reproducible and does not reliably predict the walking distance or exercise tolerance on formal testing (Criteria Committee, New York Heart Association (1964); Raphael et al, 2007).

3.6.1 EXCLUSION CRITERIA

Patients with any cognitive impairment were excluded from taking part in the study. Identification of cognitive impairments were discussed with the heart failure nurse prior to approaching heart failure patients; those who were not eligible did not take part in the study and were therefore excluded. These eliminated patients who had a diagnosis of Alzheimer’s (mild or severe) and/or trouble with memory, concentration and with making decisions that affected their everyday life due to additional co-morbidities were excluded. On occasions however, where appropriate, the family caregiver of the heart failure patient was approached with a view to being invited to participate in family caregiver interviews as part of phase 3.

3.6.2 CHARACTERISTICS OF THE PATIENTS

Eighteen patients participated in this study and their ages ranged from 19 to 79 years. Five heart failure patients were female and thirteen were male. Furthermore, nine family caregivers participated in this study with full-time responsibilities of caregiving in addition to managing and coping with other family members including extended family and family businesses. Two family caregivers were male and seven were female.

3.7 RECRUITMENT

Recruitment was undertaken via nursing staff at cardiac rehabilitation units within NHS hospital sites. A letter (See Appendices 11.5) and information sheet (See Appendices 11.1-11.4) outlining the proposed study were given to patients and family caregivers of Chronic Heart Failure. Relevant information such as invite letters, information letters and consent forms were additionally provided to heart failure patients. Researcher contact details were also provided (See Appendices 11.15). Heart failure patients were asked, in the first instance, to think about their involvement and were left with contact details. A heart failure patient information leaflet and a consent form were made available and, if acceptable, heart failure patients were asked to contact the lead researcher again to arrange a meeting (See Appendices 11.16). Consent was only formally obtained immediately prior to the interview. It was believed that having the ability to communicate and speak fluently in a language that was known to both researcher and heart failure patients would aid data collection allowing effective communication with the group being studied as evidence has shown that female Pakistanis were generally apprehensive in participating in studies which were led by males and lacked confidence in an environment which was culturally taboo (Aslam et al, 1979; Nadar et al, 2003).

Focus group discussions were carried out at two separate NHS acute trusts to obtain responses to policy changes, recommendations, and explore sensitive or cultural issues that pertained difficult to broach on a one-to-one basis (See Appendices 11.6).

Focus Group discussions included the following members:

- Maulana Saab (Muslim Religious Pastor)
- Dietician
- Pharmacist
- Heart Failure Nurses
- Cardiac Nurses
- Community Heart Failure Nurse
- Cardiac Gym Physiologist

The decision to invite and involve the Maulana (Muslim Religious Pastor) as part of the focus group discussion hailed from insightful knowledge that such an influential figure to the Muslim community had experience of ethnic, cultural and religious practices that played an integral role within the Pakistani community. As a respected leader, the Maulana was able to channel into such expertise and use his professional platform to work alongside medical healthcare professionals to impart knowledge that would encourage healthy behaviours amongst the Pakistani community. This was through the use of scripture-based messages in sermons. Such practices aided in the reduction of barriers and stigmas with which the Pakistani communities were challenged. Furthermore, the Maulana had the ability to act as an advocate for Muslim Pakistani groups whilst delivering cultural sensitivity training in hospitals. Thus, the Maulana played a key role in framing concepts of health and disease, encouraging healthy lifestyles.

The forging of healthcare partnerships with such religious leaders and their institutions might be an important means to enhance the healthcare of Pakistani Muslims. Muslim religious leaders represent an under-investigated group who might have the influential capacity to facilitate positive health change. The support of respected leaders has the ability to design and implement interventions that could aid in bridging gaps within healthcare promotion. Such gaps could increase the effectiveness of positive health promotion as part of novel strategies and interventions for health promotion encouraging policy makers to tackle and potentially reverse the problem of increasing ethnic minority health inequality.

A Dietician, Pharmacist, Heart Failure Nurse, Cardiac Nurse, Community Heart Failure Nurse and Cardiac Gym Physiologist were all invited to take part as they were key professionals to the care of patients and their family caregivers during all phases of cardiac rehabilitation care.

Unfortunately, both a cardiologist and GP were unavailable to take part due to work schedule commitments. Furthermore, a psychologist was also unavailable due to the service not being in existence to patients and their family caregivers, but only to members of staff via the occupational health department.

Attention was paid to the location, the physical environment and the composition of the room (Grbich, 1999). Members of the multi-disciplinary team were considered carefully, and key informants were selected as they collectively represented a focal role within the study's needs and of the group. It was anticipated this would encourage interaction and allow individuals to give their opinions confidently of their expert areas, as requested, providing a satisfactory discussion.

Prior to discussion commencing, a warm welcome to the group was implemented with tea/coffee and lunch. The researchers' attention to positioning was kept out of direct opposition from a dominant person of the group so that attention and eye contact was not easily made. The aim of the facilitator's eye was to be caught and firmly held intermittently whilst immersing themselves within the group. The aim of the researchers' position was held amongst those who were perhaps feeling less comfortable, shy and more reserved. This enabled the facilitator to engage the person in eye contact so that participation with verbal and non-verbal cues could be formed.

Once the focus group had been appropriately seated and refreshments had been taken up, introduction of all members was made, the topic and ethical issues of confidentiality, anonymity, the right of each individual to withdraw from the group without any penalty was stressed and the right not to respond to any question was explained clearly. Due consideration to the following, throughout the focus group, was given:

- Empathy
- Enthusiasm
- Alertness
- Confidence
- A good sense of humour
- Honesty regarding the interviewer's own biases
- The capacity to be non-judgmental
- Clarity of expression
- A strong but not too directive personality
- The ability to terminate long-winded contributions without causing offence
- The ability to encourage heart failure patients without producing discomfort

- The ability to intervene gently in heated arguments without becoming bloodied in the process.

Empathy, enthusiasm and alertness was continually applied throughout the discussion by ensuring that a genuine interest in what each health professionals conveyed was listened to attentively and reciprocated with an understanding of their experiences and expertise.

Eye contact and maintenance of body language and posture with health professionals demonstrated that they were being listened to whilst they discussed experiences. This in turn encouraged their confidence, allowing them to feel at ease which continued their engagement of discussion. The ability to provide a good sense of humour came hand in hand with the interviewer's own biases. It gave the opportunity to take on board the health professional's viewpoint whilst tactfully conjuring in differing opinions, both judgmental and non-judgmental. This in turn promoted a healthy debate of open questions to tease out a diverse range of meanings of the topic.

The focus group was recorded, and heart failure patient identification was made clear before speaking, though this may be unnatural, it become evident quite soon who was speaking at any given time as the professional role dictated discussion of relevant and specific topics. A conscious effort was made to give everyone a fair opportunity to voice their statements and expertise. In instances where health professionals discussed their experiences extensively or communicated in a language relevant to their field that others did not understand or spoke too fast, the facilitator would communicate politely the need for other members of the focus group to put forward their concerns alike, ensuring fairness and clarity to understanding what was being portrayed. My role as a moderator involved ensuring everyone participating had a chance to speak whilst being conscious of not displaying too much approval, so as to avoid favouring particular heart failure patients. Avoidance to giving personal opinions was also at the height of consciousness so as not to influence heart failure patients towards any particular position or opinion.

The role of the moderator was demanding and challenging. The ability to possess good interpersonal skills and personal qualities, being a good listener, non-judgmental and adaptable were all inter-played simultaneously. These qualities promoted the heart failure patients' trust in the moderator and increased the likelihood of open, interactive dialogue.

The facilitator consciously followed the above list in an attempt to remain fair whilst ensuring a positive experience of a focus group discussion. At times it became overwhelming as many of the healthcare professionals spoke passionately of their role and duties allowing for lesser time and attention to be given to other healthcare professionals and so when these responses diverted off topic or clashed with other professionals, I began to doubt the richness of the discussion. In light of this, probes for details were made to move things forward when the conversation appeared to drift in order to keep the session focused and steer the conversation back on course.

The maintenance of overseeing the discussion whilst respecting individual accounts was challenging despite professional insights, power and dynamic. I was conscious throughout the discussion to ensure all health professionals fed back their views. In view of those who were slightly guarded, a gentle nudge to encourage participation was given, and this was done with dialect that would diminish any obvious discomfort and pressure.

In instances where the discussion diverted towards a heated tangent, intervention to stem the tide amicably without becoming bloodied in the process was undertaken. A light-hearted tone of voice which reminded the group of the aims of the discussion, as well as highlighting the importance of respecting the value of others, their experiences and expertise, brought the dynamics and composition of the group back to its tranquil state.

3.8 THE STUDY INVOLVED

This research was conducted in Birmingham, which has a high proportion of the Pakistani population. The study involved:

3.8.1 LITERATURE REVIEW

The literature review examined existing qualitative evidence on the self-management experiences of all patients with heart disease more generally, including those with chronic heart failure.

Strauss and Corbin (1998) adopted a pragmatic approach towards using literature. They acknowledged the researcher might come to the study with background knowledge of the field, but caution against becoming constrained by the literature such that one was blinded to new emerging concepts. Instead they suggested literature could be used as a further source of data. Thus, a cautious approach was adopted in that minimal contact was made during the data collection and analysis phase. I developed an awareness of how the literature influenced me, which I attempted to minimise in my analysis by focusing on heart failure patient data.

3.8.2 QUALITATIVE INTERVIEWS

Eighteen semi-structured interviews were conducted with patients and nine with their family caregivers in their preferred language (Urdu, Punjabi, Mirpuri and English); these were transcribed verbatim. An Urdu speaking colleague verified a sample of the transcripts, which added to the robustness and validity of the data collected. Patients and their family caregivers were interviewed to share their experiences of living with heart failure. Consequently, initially two phases reflected the perceptions of patients across a time continuum: immediately post discharge and at recovery phase (post 12 weeks). Phase three of the study provided insight into the family caregivers' experiences of living with heart failure patients and lastly, phase four highlighted the perceptions of healthcare professionals via focus group discussions (see chart below showing the Phases of Data Collection). The interviews aimed to explore the experiences, understandings, and knowledge of Pakistani men and women heart failure patients to identify the barriers and facilitators to self-management in this group.

Consideration to heart failure patients' comfort was given. Individuals were encouraged to inform the researcher of any discomfort with regards to sitting for extended periods of time, which could have exacerbated their well-being. It was decided that a short break would be given to accommodate heart failure patient comfort wherever possible during the interview, both physically and psychologically. Interviews were conducted using a topic guide, which was developed using the literature review and discussions within the student and supervisory team (See Appendices 11.9-11.11). Initially there was no set number of heart failure patients required to carry out the study. Previous studies using the grounded theory method reported using between nine (Gibson & Kenrick, 1998) and 37 participants (Snelling, 1994). Within quantitative research the number of participants required was guided by power calculations. Recruiting the calculated number of participants enabled significant tests to be carried out successfully. A similar theoretical principle was at work within qualitative research, except one did not know the answer from the outset. This research recruited heart failure patients until saturation was achieved; this emerged when no additional relevant data was found and no new ideas for the development of theory arose (Holloway, 1997).

The processes of data collection, analysis, constant comparison, memo writing, and theoretical sampling continued in an iterative cycle. Recruitment of heart failure patients stopped at the point when no new concepts emerged from interviews and key elements repeated: this defined the final sample size (Corbin & Strauss, 2008). Once validation of the theory had been achieved, the recruitment of further heart failure patients became redundant.

In view of the limited time to collect and analyse data, 18 were carried out, achieving theoretical saturation.

Data generated through these interviews were analysed using the constant comparative method. This entailed close reading of transcripts and an iterative process of developing thematic categories. Initially, open codes were generated to begin to categorise the data and produce a preliminary coding frame. The computer software program QSR NVivo® version 10 (Castleberry, 2014; Gibbs, 2002) was then used to organise the data into this coding frame, which was continually evaluated, refined and added to as necessary throughout the process. The main premise of the approach was that theory emerged from, and was grounded in, the data. The honing of theory by this constant comparison process continued until a level of saturation was reached and emergent categories emerged.

3.8.3 FOCUS GROUPS

Focus groups were increasingly used to elicit the views, beliefs, or attitudes of a target population (Barbour & Kitzinger, 1999). Focus groups have been shown to be particularly useful in exploring the ways in which people collectively make sense of a phenomenon and constructed meanings around it (Waterton & Wynne, 1999). Focus groups were a strategy for collecting qualitative research data. It was a method using group interviews to generate data by group interactions, and to collect information on a designated topic (Carey & Smith, 1994). Focus groups could be invaluable to research, much interesting, rich and complex data could emerge, providing insight into a cross section of views (Cohen & Manion, 1994). Analysis of heart failure patient data was presented to healthcare professionals to help develop an appropriate intervention or educational package to support patients and their family caregivers in both a culturally sensitive and appropriate manner.

3.9 INTERVIEW AND FOCUS GROUP SCHEDULE

3.9.1 PHASE 1 INTERVIEW: CARDIAC REHABILITATION PHASE 2

Phase 1 involved an interview with patients (understanding and knowledge of HF, expectations of rehabilitation, perceptions of disease, barriers and facilitators to attending and adhering, risk factors, management of condition on a daily basis).

3.9.2 PHASE 2 INTERVIEWS: CARDIAC REHABILITATION PHASE 3

Phase 2 Interviews were with patients (adaptation, experiences, attitudes, risk factors, barriers and facilitators, self-management). Interview 2 took place post a 12-week gap of rehabilitation attendance exploring problems faced during rehabilitation (physical rehabilitation/psychological). An understanding of the process for both men and women was addressed here to assess the journey, experiences and barriers faced with a view to disseminating information as to what patients' needs were.

3.9.3 PHASE 3: FAMILY CAREGIVERS INTERVIEWS

Following interviews with patients, Phase 3 interviews with family caregivers were carried out to explore their roles, experiences of living as a family caregiver on a daily basis.

3.9.3.1PHASE 4: FOCUS GROUP

Phase 4 involved a Focus Group discussion with a team of eight health care professionals (HCPs – Multi-Disciplinary Team) consisting of a Cardiac Nurse, Dietician, a Physiologist, a Community Heart Failure Nurse, two Heart Failure Nurses, a Pharmacist and a Maulana (Imam) at an NHS trust site which fed the results of analysis post data collection to draw input which identified potential development of an informed and appropriate tool specifically for the Pakistani community living with chronic heart failure.

PHASE	STAGE	TIMELINES	METHOD OF DATA ANALYSIS	NUMBER OF PATIENTS CAREGIVERS & HEALTHCARE PROFESSIONALS
PHASE 1	INITIAL PATIENT DATA COLLECTION	STARTING POINT	INTERVIEWS	18 PATIENTS
PHASE 2	SECOND STAGE PATIENT DATA COLLECTION	CONDUCTED POST A 12 WEEK PERIOD FOLLOWING PHASE 1	INTERVIEWS	14 PATIENTS
PHASE 3	CAREGIVERS DATA COLLECTION	CONDUCTED POST DATA COLLECTION WITH PARTICIPANTS IN PHASES 1 & 2	INTERVIEWS	9 CAREGIVERS
PHASE 4	HEALTHCARE PROFESSIONALS DATA COLLECTION	FOCUS GROUP DISCUSSION CARRIED OUT POST COMPLETION OF PHASES 1,2 & 3	FOCUS GROUP DISCUSSION	8 HEALTHCARE PROFESSIONALS

The interview schedule (see chart above) aimed to cover the various aspects of cardiac rehabilitation. The self-care and management patients and their family caregivers faced were challenging and extensive. The topics of interest for the interview guide were based on the issues that would cover practice of daily life management and routine. The interview schedule guided the interviews loosely depending on how openly the heart failure patients and family caregivers wished to discuss their experiences. The topic guide acted as an umbrella covering the main over-arching areas patients and their family caregivers lived on a daily basis. Further headings (probes) were recorded to help participants along with the interviews and to keep on track of topic. The aim of the topic guide was to act as a guide, not follow prescriptively but direct discussion.

The second phase of the interview schedule was based on the topics used in the initial phase of the study. The second phase of the interview schedule used topics of interest from the first phase of the study so that data could be generated about whether patients felt that their perspectives had changed over time. As such, the topics of interest were formulated as: understanding of heart failure; perspectives on management of heart failure; perspectives on symptom management and treatment; lifestyle management of medicines, information and education, dietary, physical activity; and sources of support and on-going access of health services. The issues covered in these topics were essentially the same as described above for the initial and second stages of the study.

The interview guide was consulted with cardiac rehabilitation users, prior to data collection, to clarify any use of language that was difficult to comprehend and interpret. No extra questions or prompts were found to be required; therefore, the topic guide remained as it was. No further changes were made to the guide in the course of conducting the interviews and no technical problems occurred, mainly because a digital recorder was used instead of a cassette recorder.

3.10 PATIENT AND PUBLIC CONSULTING

Three service users, independent to the participant population where data was collected, were approached for their input. The service users attended the cardiac rehabilitation clinic as patients but were also volunteers at the cardiac rehabilitation clinic on a weekly basis. They were asked and given the opportunity to look through the topic guide questions before the roll out to participants in the study; this was to ensure that the questions were easily understood and that the language used was cardiac friendly and appropriate (see Appendices 11.7).

3.11 RESEARCH INTERVIEWS

Interviews were carried out between February 2012 and September 2012 lasting between one to two hours. All interviews were conducted in a private, mutually agreed location and time with adequate lighting and hearing distance. The extraneous occurrences outlined in the literature that could adversely affect the interview procedure, for example, equipment failures or telephones ringing (Easton et al, 2000) were safeguarded against by the choice of interview environment and the use of high quality recording equipment.

Most heart failure patients and family caregivers lived within a half to one and a half hours' bus ride from the researcher's home. The majority of the interviews were conducted in either the lounge or kitchen. Prior to beginning the interview, an introduction of the researcher was carried out to build a rapport. After introducing the topic, the researcher began to feel more comfortable and was able to engage, sit back and actively listen to what the participant was communicating (Barry, 1996). Theoretical sampling techniques were implemented, and open-ended questions became more focused. These more focused open-ended questions were in accordance with the findings to the ongoing use of the constant comparative method in data analysis. This process was supported by Glaser (1992) who stated that the researcher 'never, never asks the questions directly in interviews as this would preconceive the emergence of data' (p. 25). However, in order to obtain the maximum amount of non-forced data the research questions have to 'relate directly to what the interview is about, empirically' (p. 25).

The researcher conveyed a professional, engaging communication style during the interviews through the use of active listening techniques based on Egan's (2002) model. This model identified the importance of five proponents of active listening: sitting squarely towards participants, using an open posture, leaning forward, maintaining eye contact with participants (culturally determined), and being relaxed. Barry (1996) supported this approach claiming that participants found it difficult to share their experiences if they felt frightened or embarrassed. Each interview was audiotape recorded. Permission was sought from participants before completing each interview and it was agreed that contact may be made again to clarify or follow up on any information given during the initial interview if needed (Swanson & Chenitz, 1986).

3.12 DATA COLLECTION

Data collection of grounded theory was directed by theoretical sampling, which meant that the sampling was based on theoretically relevant constructs. It enabled the researcher to select subjects that maximised the potential to discover as many dimensions and conditions related to the phenomenon as possible (Strauss & Corbin, 1998). Grounded theory adopted an iterative approach to data collection and analysis. Therefore, following a preliminary analysis of interviews, I identified concepts needing further exploration and development. The process of checking concepts became more important as saturation approached; I have discussed this in depth within my data analysis section at a later stage. I drew on my supervision notes where we discussed emerging concepts and ideas and drew on memos. I wrote theoretical sampling memos, which I found needed doing after interviewing. The sampling memos became a place where I recorded the concepts needing further exploration. I then developed questions that could test these. I recorded these questions on an 'additional questions' schedule which I used in conjunction with the main interview schedule. As I tested out emerging concepts, I learnt these needed a context in which they were asked. I learnt how to allow participants to tell their stories, whilst thoughtfully integrating additional questions, which tested emerging concepts.

Data collection methods included semi-structured interviews with patients and their family caregivers, using theoretical and purposeful sampling techniques, field observations and documentation, memos and reflective journaling, and the review of relevant literature and reports. In addition, demographic data were collected from each patient (See Appendices 11.17). This information was based on twenty heart failure patient characteristics identifying:

- Gender
- Age
- Date of diagnosis of CHF
- Education Level
- Ethnicity
- Employment Status
- NYHA Classification
- Related Co-morbidities
- Marital Status
- Occupational Status
- Height and Weight
- Total Cholesterol (mmol/L)
- Smoking Status
- Hypertension
- Patient Attendance to Cardiac Rehabilitation
- Family History of CHD

- Hypertension
- Hypercholesterolemia
- Previous Cardiac History
- Prescribed Medicines

This data intended to facilitate and contextualise the main data analysis from heart failure patients. Obtaining this information was useful, each heart failure patient willingly provided this information at length and it successfully gave insight into each heart failure patient's medical and history.

As the study progressed concurrent analysis of incoming data guided the development of the interview schedule. Questions were refined to investigate new ideas and views which heart failure patients and their family caregivers expressed and both clarifications and inconsistencies were investigated for any gaps in the emerging themes (Corbin, 2009). The purpose of semi structured interviews in qualitative research was that they were 'conversation(s) with a purpose' (Holloway, 1997 p.94). The interviewer should ensure that the participant did most of the talking and co-constructed the conversation (Kralik, 2005). Probes and prompts may aid in keeping to the broad area for discussion. The terms and language participant used should be clarified and the interviewer should not assume shared meaning (Strauss & Corbin, 1998).

3.13 SAFE-GUARDING

Safeguarding was essential in ensuring and protecting the safety, human rights and well-being of an individual. The protection from abuse and neglect was paramount and fundamental to high quality health. This might include:

- Physical abuse (such as rough handling, unreasonable restraint, hitting, burning, pushing or kicking someone, locking someone in a room).
- Sexual abuse (such as inappropriate touching or forcing someone to take part in or witness any sexual act against their will).
- Psychological/Emotional abuse (such as intimidation, bullying, shouting, swearing, taunting, threatening or humiliating someone).
- Financial abuse (such as theft, fraud, coercion over wills, misusing someone's money, property or other belongings without their agreement).
- Discriminatory abuse (such as ill-treatment or harassment based on a person's age, sex, sexuality, disability, religious beliefs or ethnic group).

- Institutional abuse (through rigid regimes, systemic poor care, poor organisational culture, lack of resources, denial of choice, lack of dignity and respect for service users).
- Modern slavery (such as slavery, human trafficking, forced labour and domestic servitude).
- Domestic violence (including psychological, physical, sexual, financial, emotional abuse; so-called ‘honour’ based violence).
- Self-neglect (including failure to provide adequate provision that meets personal care needs such as food, living space and hygiene).

Safeguarding has to be ‘Everybody’s Business’. The Care Act 2014 has placed adult safeguarding on a statutory footing and the law now stipulates very clearly that it has a duty to co-operate, to work together and to share information in order to deliver safeguarding responsibilities. Every practitioner has a part to play in this.

There are an array of factors and reasons as to why abuse has occurred and/or existed; it has not always been an intentional or a deliberate attempt to cause harm. It could arise out of stress, insufficient resources or lack of knowledge and skills. But abuse was often perpetrated in circumstances where one person (or persons) had power or control over another individual. These persons could be a spouse; partner; son; daughter; relative; friend; carer or neighbour; a paid carer or volunteer; a health worker; a social care worker; another resident or service user; a visitor or someone who was providing a service to the person. Abuse could take place anywhere: in a person’s own home, in day or residential centres, in supported housing, educational establishments, nursing homes, clinics and hospitals. It could occur on public transport, on the street or in other public spaces. Empowering people to make their own decisions about the way they live and the care they receive has been fundamental good practice. It has given people better outcomes and an improved sense of wellbeing. Safeguarding must apply the same principles and should be no different; safeguarding should not be a process of application to people, but instead it must be a rapport that has by nature empowering decision-making, based on their own terms (Birmingham Clinical Commissioning Group, 2019).

I ensured that I reported to my supervisory team and colleagues prior to conducting any interviews at a location where I would be off-site from university or home, namely the premises of the patient and or family caregiver’s residence. I carried with me my mobile phone and a personal attack alarm. This was to ensure a safe and good quality of self-care and to avoid risk of harm (www.cqc.org.uk/content/safegaurding-uk).

Acknowledgement and awareness of unexpected strategies were sought by the researcher, via means outlined below in a robust manner:

- Counselling Services (University approved)
- Cardiac Support Services
- Supervisor and Mentor University/Cardiac Unit
- Ensure safety by informing supervisor/colleague of location and time of interview and carrying a personal alarm.

The above support networks were put in place to ensure that if concerns relating to the study posed issues, the services and correct people would be contacted to help mediate and resolve any concerns. The Suzy Lamplugh guidelines were followed to ensure researcher safety (Suzy Lamplugh Trust Offer, 2010).

3.14 ETHICAL CONSIDERATIONS

The proposed study gained subject to ethical approval outlined by Birmingham City University Ethics Committee and NHS Ethics – Black Country Research Ethics Committee and R&D – City & Sandwell Hospital NHS Trust (See Appendices 11.18-11.21).

The study under-went ethical review in the NHS and sponsorship was sought via the Faculty of Health’s Sponsorship Committee in order to ensure the interests, safety and wellbeing of participants. It was necessary that this study adhered to:

- Respect
- Competence
- Responsibility
- Integrity

The Code of Ethics and Conduct (British Psychological Society (BPS), 2006) has been based on four ethical principles, which have constituted the main domains of responsibility within which ethical issues have been considered by the British Psychological Society. These guidelines (BPS, 2006) were followed accordingly and adhered to. Ethics in research has been related to moral standards. Ethical concerns have to be considered in all research methods and at each stage of the research design. Ethical issues have been important in relation to the aim or the research question. Researchers applied principles that protect the participants in the research from harm or risk and follow ethical guidelines and legal rules/the rights of the individuals were that they were not to be harmed, that they gave their consent on the basis of information and knowledge about the research, that their participation was voluntary, and that the researcher followed the rules of confidentiality and anonymity (Wilkinson, 1995). It has been good practice for studies, involving people as participants, to be ethically reviewed. In some cases, this was a legal requirement to safeguard the rights, dignity and welfare of people participating in research. NHS Research Ethics Committees (RECs) and Integrated Research Application System (IRAS) were responsible for undertaking these ethical reviews and were independent in membership of the researcher and the organisations funding and hosting the research (University) and other NHS management and R&D Offices.

It was not anticipated that any major ethical problems would be encountered. However, with qualitative research it might be the case that whilst undertaking data collection and carrying out interviews with participants and family caregivers they might become upset whilst discussing their condition and self-management of daily living. There might be issues concerning coping, taking medication, relationship dynamics with family and/or management of risk factors.

Participants were informed that withdrawal from research was an option at any time. Participants were offered breaks should they have wish to stop at any time during their interview. This was also the case for the researcher. For example, if the content of the interview became a little demanding the interview was terminated or paused depending on preference of participant. The researcher had experience of dealing with sensitive issues and it was anticipated that this would help equip the researcher to tackle such problems if they arose. However, access to the supervisory team for debrief of any concerns was an option after the interview took place.

Interviews could sometimes reveal details of participants making it easy to identify participants. Care was taken to remove such detail by disguising personal demographic information which, anonymised patients and their family caregivers by the use of pseudonyms. All biographical details and consent forms were kept securely and separate from interview data, making all information secure. Access was restricted to the researcher only. All participant data was managed and handled with confidentiality in accordance with the Data Protection Act (1998).

3.15 VOLUNTARY INFORMED CONSENT

Voluntary informed consent means that the individual has decided to participate in the research on his/her own accord. It was essential that this decision be made without coercion or undue influence by the researcher (Orb et al, 2001). In addition, Bachelor and Briggs (1994) reported that people continued to participate, even when they experienced stress, because they felt morally bound to do so.

Voluntary informed consent could only be obtained when the participant had been given essential information regarding the study and had demonstrated an ability to comprehend this information, thus ensuring his/her competence to give consent. What researchers intended to do with the findings of the study needed to be clearly explained to the participant prior to obtaining informed consent (Munhall, 1988). All original consent forms were kept in a filing cabinet to which only the researcher had access.

Although voluntary informed written consent was obtained from participants there was a broader concept of informed consent posed by the use of qualitative research methodologies. According to Ramos (1989), the emergent designs of qualitative research and data collection methods made the direction that research would take to a large extent unknown. Therefore, the use of an ongoing process of consensual decision-making in this study was paramount. This allowed participants to be kept informed about their vulnerability to potential dangers of emotional distress. The service of support strategies would be offered to any participants should they require this service.

3.16 INFORMED CONSENT

Consistent with its commitment to individual autonomy, social science in the Mill and Weber (Heidelberger, 2010). tradition insisted that research participants have the right to be informed about the nature and consequences of the study in which they are involved. A respect for human freedom consisted of two conditions. First, participants must agree voluntarily to participate, that is, without physical or psychological coercion. Second, their agreement must be based on full and open information (Denzin & Lincoln, 1994). ‘The Articles of the Nuremberg Tribunal and the Declaration of Helsinki’ both stated that subjects must be told the duration, methods, possible risks, and the purpose or aim of the experiment (Denzin & Lincoln, 2001; see also Orb et al, 2001). In empathizing informed consent, the element of deception must be removed. Bulmer-Thomas (1982) was typical of hard-liners who concluded with the code that deception was ‘neither ethically justified not practically necessary, nor in the best interest of sociology as academic pursuit’ (p. 217; see also Punch, 1994, p. 92).

Privacy and confidentiality was an essential criterion in safeguarding people’s identities and research locations. The Code(s) of Ethics and Conduct (BPS, 2006) highlighted this as essential and vital. Confidentiality must be assured as the primary safeguard against unwanted exposure. All personal data was made secure and concealed and made public only behind a shield of anonymity. Professional etiquette uniformly concurred that no one deserved harm or embarrassment as a result of insensitive research practices (Denzin & Lincoln, 1994). ‘The single most likely source of harm in social enquiry’ was the disclosure of private knowledge considered damaging by experimental subjects (Riess et al, 1984, p. 73; see also Punch, 1994, p. 93). Ensuring the accuracy of data was a cardinal principle in social science codes; fabrications, fraudulent materials and omissions, and contrivances were all non-scientific and unethical. Data internally and externally valid were the coin of the realm, experimentally and morally.

The voluntary informed consent of research participants was essential. According to Rolfe (2006) ‘informed consent means that participants have adequate information regarding the research; are capable of comprehending the information; and have the power of free choice, enabling them to consent voluntarily to participate in the research or decline participation’ (p. 134). Burns and Grove (1999) described a four-stage process to obtain informed consent:

- Disclosure of essential study information
- Comprehension of this information by the subject
- Competence of the subject to give consent
- Voluntary informed consent of the participant
- The need to be informed.

Disclosure of essential information at the participant’s level of comprehension was necessary in any kind of research. The participant should be informed about the purpose of the research, about any risks or discomfort that he/she might experience, as well as the benefits of the research being undertaken (Munhall, 1988). Information regarding the objectives of this study was presented to cardiac rehabilitation clinics at three separate NHS sites where initial contact with participants was made. During this stage, the purpose and focus of the study was outlined, fully describing what participation involved and what the role of the participants involved. Informed consent was obtained post successful comprehension of the information given concerning the study. A length of time to answer questions in order to facilitate this process was provided. According to Streubert and Carpenter (1999), it was essential that researchers and participants discussed and clarified their understanding of the research to be conducted. In addition, Alty and Rodham (1998) considered that this process was essential as even under the best research circumstances it was difficult to determine if the researcher and the participant had a common understanding of the topic being researched.

Prior to any interview being conducted, the information sheet was given to participants via the nursing team at the cardiac rehabilitation clinics. Participants were given sufficient time to read the information sheet regarding this study. The participants were encouraged to contact the researcher if they had any concerns they wished to discuss. The option of withdrawal or to refuse to answer any questions without penalty was also discussed. No coercion was used at any time to encourage any participant to become involved in the study; it was entirely their choice. When participants stated that they were fully informed and happy to participate in the study only then were they asked to sign the consent form prior to the interview commencing (See Appendices 11.12-11.14).

It was anticipated that this process will be beneficial in developing rapport with the participant as well as making them feel empowered regarding their role in the interview process. Batchelor and Briggs (1994) suggested that the participant was the least powerful person in the research process and that many of them participated only to help others. Therefore, procedure was followed to ensure efficacy.

3.17 PARTICIPANTS' LEVEL OF COMPETENCE TO GIVE INFORMED CONSENT

It has been generally accepted that individuals who had diminished autonomy due to legal or mental incompetence, terminal illness, or those confined in institutions might not be legally competent to consent to participate in research (Burns & Grove, 1999). All participants in this study were over the age of 18 years and had no cognitive impairment that affected their ability to understand the researcher, or to express their perceptions concerning their experience living with chronic heart failure. All participants spoke a language of their preferred choice whilst being interviewed.

3.18 WITHDRAWAL FROM THE STUDY

All research participants had the right to withdraw their consent (either verbal and/or written) at any time. When the decision to withdraw consent was made, the participants would not be coerced or put under any influence by the researcher to continue. Furthermore, participants would not have to provide any reasons as to why they decided to withdraw, and the withdrawal of consent incurred no consequences for the participant. If requested, any audiotape recordings of the interviews, written material, and field notes pertaining to the participant would be destroyed. No participants withdrew from this study or requested that any information given to the researcher be erased or destroyed.

3.19 PRIVACY, CONFIDENTIALITY, AND ANONYMITY

Anonymity and confidentiality were an integral part of the research process. Anonymity occurred when participants' data was not linked to their identity. However, in qualitative research methodologies it was difficult to achieve this because the researcher knew the identities of participants (Streubert & Carpenter, 1999). Therefore, the researcher ensured that their identities remained confidential. In this study a code number and pseudonyms were assigned for each participant. Reference to a health service, doctor, or a family member or significant other that might have revealed the identity of participants was omitted. Confidentiality in research meant that private information identifying the participant would not be reported unless the participant had agreed to the release of this information (Kvale, 1996). Confidentiality was linked closely to the concept of beneficence, or that the risk of harm to the participant was the least possible. Confidentiality was based on the premise that:

- Individuals could share personal information to the extent they wished and were entitled to have secrets
- One could choose with whom to share personal information
- Those accepting information in confidence had an obligation to maintain confidentiality
- Professionals, such as researchers, had a duty to maintain confidentiality that went beyond ordinary loyalty (Kvale, 1996).

Audiotapes of recorded interviews were kept in separate locked cupboards. All participants were told that the only person to have access to their data would be the researcher. Prior to conducting an interview, the contact details of the participant's address and contact details of researcher were emailed and left with a member of the supervisory team. Before commencing an interview, it was agreed that if the participant wished to stop the interview at any time he/she would raise their hand in the air and this would suffice to inform that the interview should stop. As a researcher, it was a privilege to listen to participants' experiences, which might induce emotional distress. The experiences told conveyed both strength and courage by participants who had maintained their dignity and integrity through their difficult circumstances. While listening to these experiences it could never guaranteed that the researcher would not experience distress.

The distress was a component of conducting qualitative research. The distress allowed the researcher to further comprehend the dimensions of the experience that was being researched, aiding analysis of the processes and interactions that might not have been as sharp if the distress had not been experienced. In other words, the experience helped facilitate personal growth and a widening of perception of the participants' experiences of managing and living with chronic heart failure, increasing the researcher's theoretical sensitivity.

3.20 POSITIONALITY AND REFLEXIVITY OF RESEARCHER

'It is critical to pay attention to positionality, reflexivity, the production of knowledge and the power relations that are inherent in research processes in order to undertake ethical research' (Sultana, 2007, p.380).

'Interpretive research begins and ends with the biography and self of the researcher' (Denzin, 1989, p. 12).

The term positionality described both an individual's view and the position they have chosen to adopt in relation to a specific research task (Foote & Bartell, 2011; Savin-Baden & Howell-Major, 2013). The individual's view or 'where the researcher is coming from' concerns ontological assumptions (the nature of social reality), epistemological assumptions (the nature of knowledge) and assumptions about human nature and agency (Opie & Sikes, 2004). These were 'coloured' by values and beliefs such as: political allegiance, religious faith, gender, sexuality, historical and geographical location, race, social class and status, (dis)abilities (Wellington et al, 2005; Opie & Sikes, 2004).

Positionality

'...reflects the position that the researcher has chosen to adopt within a given research study' (Savin-Baden & Howell-Major, 2013 p. 71) and was normally identified by locating the researcher in relation to three areas: the subject, the participants and the research context and process (Ibid p. 71). Some aspects of positionality were culturally ascribed or fixed, for example, gender, race, nationality; whilst others such as personal life history and experiences are subjective and contextual (Chiseri-Strater, 1996).

The fixed aspects might predispose someone towards particular point(s) of view; however, that does not mean that these aspects necessarily automatically led to particular views or perspectives. For example one may think it would be unethical for a black African-American to be a member of a white, conservative, right wing, racist, supremacy group, and that such a group would not want African-American members; yet Jansson (2010) in his research on 'The League of the South' found that not only did a group of this kind have an African-American member, but that he was '...warmly welcomed...' (p.21).

Positionality has required that both acknowledgement and allowance was made by the researcher to locate their views, values and beliefs in relation to the research process and the research output(s). Self-reflection and a reflexive approach were both necessary prerequisites; an ongoing process for the researcher to be able to clearly identify, construct, critique and articulate their positionality was essential. Reflexivity, the concept that researchers should acknowledge and disclose their own selves in the research, seeking to understand their part in it, or influence on the research (Cohen & Manion) et al, 2011, p. 225) has informed positionality. Reflexivity required an explicit self-consciousness and self-assessment by the researcher about their own views and positions and how these might have influenced the design, execution and interpretation of the research data findings (Greenbank, 2003).

Reflexivity was the process of reflecting critically on the self as the researcher, the 'human as instrument' (Guba & Lincoln, 1989). Reflexivity referred to a critical examination of own assumptions and actions through being 'self-conscious' and self-aware about the research process. This monitoring process included reflection about reaction to the people and events in the setting (Holloway, 1997). Practically speaking, this included reflecting upon relationships with participants in addition to examining their own feelings whilst carrying out the research and the effects of observations on the participants under study. Explanations were offered for making certain decisions. Reflexivity was essential in qualitative research as the researcher was the main research tool; he or she 'uses the self' as an instrument (Holloway, 1997).

Potter (1996) listed three strategies of reflexivity. In the first, the researcher gave details of the research process and the context of the research (audit trail). The second involved the author in a reflection on the methods while taking a self-critical stance towards the interpretation of the data. The third consisted of the disclosure of assumptions and biases. It was necessary, therefore, to realise that researchers were part of the reality they investigated, and that they should reflect their own location in the culture, time and place. Consciousness of actions and interactions, in addition to the roles adopted in the field must be held close (Holloway, 1997). A major element of qualitative inquiry was affected by the social location of the researchers, their personalities and values. It was important to be aware of, reflect on own preconceptions and assumptions while attempting to understand the effect they had on the data. The process of reflection also acted as an aid to uncover contradictions and paradoxes.

The journey of reflexivity was a conscious experience of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the processes of research itself. Reflexivity encouraged the self to become engaged within the research process with the multiple identities that represented the fluid self in the research setting (Alcoff & Potter, 1993). Reinharz (1997), for example, argued that we not only 'bring the self to the field … [we also] create the self in the field' (p. 3). The author suggested that there were three types of categories in which the self was brought into the study field: research-based selves, brought selves (the selves that historically, socially, and personally created our standpoints), and situationally created selves (p. 5). Each of those selves came into play in the research setting and, consequently, had a distinctive voice. Reflexivity demanded a questioning and interrogation of ourselves which helped facilitate and shape identities in the field with respondents in addition to the process of becoming ourselves providing a mixture of both advantages and disadvantages. The advantages of multiple selves gave rise to more dynamic, problematic, open-ended, and complex forms of writing and representation, whereas the disadvantages of multiple selves created and gave rise to more dynamic, problematic, open-ended, and complex forms of writing and representation (Denzin & Lincoln, 1994).

Reflexivity entailed sensitivity to the researcher's cultural, political, and social context (Bryman, 2012, p. 393) because a researcher's ethics, personal integrity and social values as well as their competency influenced the research process (Greenbank, 2003, p. 278). Through the process of reflexivity, researchers should continually be aware that their positionality was never fixed and was always situation and context dependent. The process of reflexivity and positionality is never fixed and is always situation and context dependent, nevertheless reflexivity was an essential process for shaping positionality as it suggested that researchers should acknowledge and disclose their selves in the research, aiming to understand their own influence on and in the process; rather than trying to eliminate their affect. A researcher's positionality not only shaped their own research, but influenced their interpretation, understanding and ultimately their belief in the 'truthfulness' of other's research that they read or to which they were exposed.

Open and honest disclosure and exposition of positionality showed where and how the researcher believed that they had influenced their research. The reader was then able to make an informed judgement as to the researcher's influence on the research process and how 'truthful' they felt the research was.

Three primary ways of accomplishing positionality included:

- Locating self in relation to the subject i.e. acknowledging personal positions that had the potential to influence the research.
- Secondly, locating self in relation to the participants i.e. each researcher considered how they viewed themselves, as well as how others viewed them, whilst

acknowledging that individuals might be unaware of how they and others had constructed their identities.

- Thirdly, locating self in relation to the research context and process i.e. acknowledging that research would necessarily be influenced and would be influenced by the research context (Savin-Baden & Howell-Major, 2013, pp. 71-73).

Fully aware that my positionality would affect my research, below are accounts of the impact this had upon my understanding, interpretation, acceptance and beliefs.

A critical reflexive stance, which paid close attention to my own positionality, aimed to explore the subjective experiences of patients and their family caregiver's daily living and managing heart failure. Pakistani patients and their family caregivers were vulnerable based on a range of demographic, social and economic circumstances which rendered them to discrimination and marginalisation. Discussion of managing heart failure elicited several sensitive details married with much frustration. Factors such as communication barriers and cultural identities highlighted insight the Pakistani populations' experiences of living with heart failure and the challenges they faced.

Undertaking this study was difficult, listening to the emotional hardships endured by patients and their family caregivers gave insights of much distress of managing medicines, diet, mobility and loss of role. Patients spoke fondly of their loss of former role and the importance of their identities that had been stripped away from them. In particular, a patient who was of college age (19 years) was especially difficult to interview. This particular female was challenged with multiple co-morbidities in addition to severe difficulties of heart failure so hearing the emotional accounts specially over the physical difficulties made it really upsetting to comprehend the experiences of living with heart failure and the daily battle that it was that had overtaken her life. For example, dietary needs were compromised due to diabetes (type 1, insulin dependent); college was intermittent as was physical activity due to symptomatic difficulties and thalassemia (monthly blood transfusions). However, the participant's spiritual belief remained firm in faith which came across in her interviews; this helped with her family dynamics which often were a cause of contention due to medication adherence and sibling rifts. This level of positivity acted strongly as a coping mechanism and broke down the barriers of depression, this was highly admirable though transparent to see temporary with frequent lapses.

The family caregivers participating shared sensitive issues of their loss, worry and anxieties of losing their independence and role within their relationships. A memo from my field notes illustrated the impact this had on me following an interview where a participant revealed her daily experience of living with heart failure and the cultural pressures that tore their consciousness apart.

I grasped every emotion of the family caregiver; I felt deep sorrow and helplessness. I was also crippled with frustration that so many burdens were clouding her conscious, especially those that the external communities and family members placed. I left the interview mentally exhausted and emotionally drained. I understood the physical drain of caring for a patient that had medical issues and as a result debilitating symptoms and required care but what I struggled to agree with was the judgment that burdened her, the expectations and cultural pressures that extended family and community members held. This type of guilt imprisoned further family caregivers to the extent of developing depression and clinical anxiety. I questioned whether I should be interviewing the level of guilt and burden family caregivers were carrying and the reliving of upsetting distresses that overwhelmed them. I wondered how I could encourage the family caregiver to feel empowered and proud of her role and that seeking under such difficult circumstances, that asking for help was not a limitation regardless of the judgment. This family caregiver in particular could not cope or manage an elderly family member in addition to her partner and four sons and mother-in-law as well as coping with her own chronic illness. With much guilt burdening her, her hope was to seek help that would put support measures in place including respite. This was shunned upon and her role as a family caregiver was compromised and questioned by external members of the family and community who felt failure and ‘letting’ down this patient would follow. Subjecting to the support of agencies would be culturally a failure and ‘shame’ that would reflect negatively upon the family. This type of dishonour would be shameful and dishonourable.

Prior to interviewing, I had anticipated that cultural heritage of the Pakistani population would impinge on living with heart failure, however what I did not prepare for was the level of deep discomfort and pain it would be for them to share and for me to comprehend especially as I resided in a ‘world’ where I am aware of both the Western culture that helped to medically alleviate matters relating to health and personal distress and a culture that ‘picks and chooses’ help burdening women with cultural expectations. I struggled with the clash of these two; whilst I understood them, it was frustrating to experience the suffering of women. I felt what they felt, in between a rock and a hard place.

Nevertheless, I maintained a sense of comfort for the heart failure patients and family caregivers made every effort to act professionally. I met regularly with my supervisors, and de-briefed with health professional teams and fellow PhD colleagues and so was able to talk through any feelings of anxiety I was experiencing and off-load emotionally the sensitivity of interviews as on numerous occasions I felt helpless regardless of my best efforts to listen to them and reassure them of their much contributed functional and caring role. Furthermore, I limited myself to undertaking only one interview per day.

The experience of interviewing awakened me to the depth of the role a researcher played, the importance of having relevant skills and understanding to work with data that was difficult has proved supportive through the access to expert debriefing consultations, the importance of a reflective journal also became clear. Each session was debriefed for reflection and the picture painted brought together the whole story systematically aiding the process of positionality.

3.21 FIELD NOTES

Glaser and Strauss (1967) noted the importance of fieldwork and the resulting documentation, claiming it provided ‘real life character’ (p. 226). The ‘first hand immersion in a sphere of life and action - a social world - different from one’s own yields important dividends’ (p. 226). Furthermore, the researcher who had observed closely in this social world had been sufficiently immersed to know it while remaining detached enough to think ‘theoretically’ about what will be observed (p. 226). This detachment allowed the researcher to be protected against ‘going native’ but allowed him/her to pass as a ‘native’ to a large extent (p. 226). In this study, the researcher was an experienced hospital-based placement volunteer. This facilitated the attribution of balance in the role as a researcher.

During and following the interview process, information pertaining to relevant observations made during the interview was documented by the researcher. The focus of the observations included the environmental setting of the interview and the verbal and non-verbal communication used during the interview. For example, the level of eye contact or the participant’s tone of voice. In addition, if family members were home, the interactional processes were observed between the family caregivers and their family member(s). Field notes added important contextual content to the study and the researcher’s audiotape-recorder was left on during the journey home as the full impact of the interview began to emerge. Field notes were kept as part of data collection and helped the researcher to remember the particular circumstances of individual interviews. Field notes aided in the subsequent thought processes required in analysis. A reflexive journal was also kept helping the researcher consider where she positioned herself in the study. This reflexive process raised awareness of the possibility of one’s own views and ideas influencing data collection and analysis. Together, the field notes and the reflexive journal offered an effective audit trail, which gave cohesion and rigour to the study (Holloway, 2009).

3.22 DATA ANALYSIS

Strauss and Corbin (1998) offered a sequence of analysis which guides the researcher through their initial open coding of data; the development of concepts and categories; the subsequent development of links between and within categories (axial coding); and finally through selective coding the development of a core category under which the remaining categories sit. In line therefore with Strauss and Corbin's (1998) guidance, the researcher observed their proposed method in a fluid rather than rigid manner. The researcher adopted the principles of theoretical sampling and data saturation. These helped in assuring the emerging model was robust.

In contrast to other qualitative methods, data collection and analysis formed an iterative spiralling process in grounded theory. I started the analysis process following the first interview. This informed the conduct of subsequent interviews. In this section I have explained some of the major decisions I made regarding the analysis. Furthermore, I have highlighted how concepts emerged from the data and how I used grounded theory principles to develop these ideas. I have explained how I came to the decision to stop collecting data, following my belief in saturation. I have then described the analytical process that continued into the stage of writing up my results. I have presented this account chronologically to provide an integrated account of my analytical decisions. Furthermore, I have highlighted the steps I took to examine and minimise my own assumptions and biases, to prioritise the participant's voice.

Post completion of interview, tape recordings were replayed as soon as possible to check for quality and content. A biographical sheet was completed for each heart failure patient and comments were written of the researcher's perception of each interview. Notes were made of questions raised for further exploration with future respondents. All tapes were transcribed verbatim using VLC Media Player software and checked for any gaps and errors. Interviews were transcribed to enable coding to take place. I followed supervisory advice and transcribed the interviews myself; this was a lengthy process and required perseverance, it took somewhere between 7-9 hours per interview tape. I benefited from an increased familiarity with the data. Analysis started after the first interview had been completed and continued concurrently with data collection, both becoming interdependent as the processes developed. I read through the transcripts once before I started to open code to identify similarities between what the participants had said, this process was known as line-by-line reading.

Strauss and Corbin (1998) recommended conducting a line-by-line analysis in the early phase of the research to help generate initial concepts. Once an interview was transcribed each line was analysed by the researcher for as many codes as might fit the data (Glaser, 1978b). This coding helped to build ideas inductively and kept a focus on the data (Charmaz, 2000). Furthermore, Charmaz (2000) claimed, ‘it helps us to remain attuned to our subjects’ views of their realities, rather than assume that we share the same views and worlds’ (p. 515). Beginning with no pre-identified categories, the open coding method broke down the data into codes representing meanings of phenomena. Code words were written on the transcribed interview on the wide margins provided on the printout from the computer software program QSR NVivo® version 10 (Castleberry, 2014; Gibbs, 2002). The iterative approach adopted with early interview transcripts meant that the subsequent interviews were addressed with minor tweaks, namely the probes within the topic guide. The recursive process informed subsequent interviews which addressed the needs of both the methodology process and the study. This process was completed with all transcribed interviews. Codes were mainly descriptive in character (Glaser, 1978b) and referred to substantive codes (Hutchinson, 1986). In addition, during the coding process, memos assigned to these codes were written in a separate codebook. The memo identified if the code was being used for the first time or if it had occurred previously in the data linked to another participant.

These codes were then compared and contrasted for similarities and differences in other parts of the interview and with interviews conducted with other participants (constant comparative method). According to Glaser (1992), this stage of data analysis should be used to identify the category or property of a category to which data being analysed belonged. Data were broken down into phenomena and these phenomena were closely examined for differences and similarities which influenced subsequent interviews.

Using the constant comparative method comparisons of phenomena to phenomena, phenomena to concept and the formulation of categories and their properties were completed (Glaser, 1992; Strauss & Corbin, 1990).

Training of NVivo computer software (Castleberry, 2014; Gibbs, 2002) was used to aid the initial process of sifting through the transcripts to manage, shape and make sense of unstructured information. The researcher uploaded and analysed transcripts in NVivo and stored these in NVivo. As transcript quotes were often included in memos, the researcher used NVivo to cross-reference these to the appropriate sources. This involved highlighting passages of text that were examples of categories and cross-referencing these to similar passages from other transcripts to begin to develop the overall structure of categories and sub-categories capturing their dimensions. This was in line with principles from Strauss and Corbin (1998) to organise data into categories and sub-categories. NVivo names these categories: free nodes and tree nodes.

The researcher used the software to assign free codes to transcript data which later facilitated the process of the write-up stage as extracts of quotes supported the analysis. The researcher organised data by developing codes and subsequent definitions for each code. This started the process of developing a long catalogue of open codes (Strauss and Corbin, 1990). This involved forming initial categories of information about the phenomena being studied from the data gathered. This was 'the process of breaking down, examining, comparing, conceptualizing, and categorising data' (Strauss and Corbin, 1990, p. 61).

The high functionality of NVivo, its flexible nature and, moreover, its suitability for a grounded theory study led the researcher to believe it represented a good option. The program was found to be user-friendly and considerably versatile to use than other analytical approaches, such as cutting up transcripts and pasting passages of text on larger pieces of paper or using coloured highlighter pens to mark passages of text. It was worth mentioning here that the use of NVivo computer software in no way detracted from the demanding mental processes required in analysis, it merely aided the process.

As data were collected categories were refined by merging initial categories and their properties into smaller sets of more abstract categories (Fleury et al, 1995). The process of examining, comparing, conceptualising and categorising data via sentences, phrases, and paragraphs took place, thus developing codes which led to clustering of codes and formation of categories. The development of categories defined properties and dimensions, known as axial coding and lastly developing themes that supported the data (De Laine, 1997).

Glaser and Strauss (1967) pointed out the constant comparative method of analysis used in grounded theory. According to Haig (1995) the constant comparative method was an:

'amalgam of systematic coding, data analysis and theoretical sampling procedures which enables the researcher to make interpretive sense of much of the diverse patterning in the data by developing theoretical ideas at a higher level of abstraction than the initial data descriptions' (p. 5).

When using the constant comparative method, data collection, coding, and analysis occur concurrently throughout the research (Streubert & Carpenter, 1999), using a four-stage process:

- Comparing incidents applicable to each category;
- Integrating categories and their properties;
- Delimiting the theory, and
- Writing the theory (Glaser & Strauss, 1967, p. 105).

Two steps are basic to the constant comparative method of coding. Firstly, phenomena must be continually compared for similarities and differences and when concepts emerge this process must be repeated (Strauss & Corbin, 1990). The second step undertaken by the researcher was to continually decide which category or property of category the phenomena being analysed belongs to, and then name this category. These two steps ensured the generation of categories and their properties from the data (Glaser, 1992).

Furthermore, they highlighted the need for any expansion of the theoretical sample to further clarify, define, or consolidate categories and properties identified through open coding. Chenitz and Swanson (1986) claimed that by using this method of analysis it was possible for the researcher to ‘progressively focus the research as data becomes clearer’ (p. 18). The result was a ‘theory which describes the core category that characterizes [sic] the behaviours [sic] of the group’ (p. 18).

In addition to the notes made after each interview, the researcher kept a journal of reflections and thoughts about interpretations of the data, which included diagrams of relationships between emerging categories to guide or reflect the analysis. This was found to be a highly useful way of recording thoughts that could be referred to later when reflecting on new data or new ideas. A considerable amount of time was spent thinking about the relationships between concepts in the data, the properties of themes and variations in the data. This in turn prompted further scrutiny of the transcripts and then further examination of the themes to ensure that the analysis was thoroughly grounded in the data and preconceived ideas were not being forced upon the data.

This process continued throughout the study up to and including the stages of writing up, as further insights were gained (Charmaz, 2006). The researcher started using memos to explore key concepts emerging in the data. The use of the constant comparison technique proved fundamental within stories.

Constant comparison has been integral to the grounded theory approach (Glaser & Strauss, 1967). A tight mesh of horizontal and vertical comparisons occurred to provide rigour and consistency. Horizontal comparison was achieved as each transcript was compared with all others to confirm ideas and views and to develop categories. Vertical comparison began to occur as the investigation progressed and abstract categories developed (Charmaz, 2006). These were constantly compared to incoming and previous data in order to confirm, challenge and refine the emerging theory and identify any conflicts (Locke, 2001). This facilitated the progressive focussing of the study as concepts grounded in the data were gradually shaped to form an abstract conceptual explanation. Thus, a theory was sufficiently developed.

Interview transcripts were compared with the themes identified to examine the similarities and differences in detail. Coding was not sequential; it overlapped. After collecting additional data, the researcher returned to analysing and coding data, which gave insights into the analysis process to inform the next iteration of data collection. This process continued until a strong theoretical understanding of an event, object, setting or phenomenon emerged. This resulted in the analytical categories being modified accordingly so that the properties of each category were more clearly defined or refined. Categories were compared with each other and relationships between them were identified and examined in detail in order to develop an overall structure.

Strict care was taken to account for views or experiences that differed from the majority view, a process referred to as deviant case analysis (Charmaz, 2006; Mays & Pope, 2000). By comparing deviant views with the majority view, the properties of categories were further refined and a clearer interpretation of the data was formulated.

Writing on-going memos assisted the researcher in reviewing data and considering subsequent activity. Memos were considered as records of the internal conversations the interviewer had with herself (Lempert, 2010). They assisted in developing abstract thinking. Diagrams formed part of the memo writing process. This assisted in making visual some of the interpretations that emerged from the data as links were made and categories developed (Locke, 2001). These processes assisted in identifying gaps in the data, which required further investigation and helped to direct theoretical sampling (Holloway, 2009). Memos and diagrams also formed an integral part of the data because they demonstrated the reflective and interpretive processes being undertaken and this acknowledged the researcher's part in the co-construction of theory (Charmaz, 2006).

Axial Coding involved assembling the data in new ways after open coding. It explored the codes and the connections between them to see if they were related or co-existing. Coding families, including Causes, Contexts, Contingencies, Consequences, Covariances and Conditions were developed. The basic social psychological problem of being consumed emerged and the coding families identified the links to other categories; for example, 'medication adherence', 'understanding medicines', and 'trust in healthcare professionals' (see Appendices 11.26 for an illustration of mapping).

Validation of this process was continually carried out by reviewing the data and through the further exploration of concepts with participants (theoretical sampling). During this stage of analysis, data were perceived theoretically instead of descriptively and the analysis involved a two-stage process: sorting and saturation. Firstly, the intent of sorting, according to Glaser (1978a), was to 'weave the fractured story back together again' (p. 72). 'Weaving' was sorting theoretical memos and the coding families. Secondly, the process of reaching saturation occurred when delimiting features of the constant comparative method began. This involved two stages: the theory ‘solidifies in the sense that major modifications become fewer’ (Glaser & Strauss, 1967, p. 110), and later modifications to clarify and elaborate on details of ‘properties into the major outline of inter-related categories and most important – reduction’ (p. 110).

The process of selective coding then followed which involved the integration of the categories in the axial coding model. In this phase, conditional propositions were typically presented. The result of this process of data collection and analysis was a substantive-level theory relevant to a specific problem, issue or group. It was ‘the process of selecting the core category, systematically relating it to other categories, validating those relationships, and filling in categories that need further refinement and development’ (Strauss & Corbin, 1990, p. 116). Once a core category arose from the data and the data determined its properties and relationships to other categories, the analysis shifted to the identification of the relationships of a single category to all other categories. Selective coding was then used to systematically link all other categories to the core category. This process might uncover and clarify additional categories and might also lead to further data collection through theoretical sampling techniques (Heuser et al, 1999) According to Strauss (1987) six criteria have been used in the process:

- The core category must be central to and related to as many other categories and their properties as possible
- The core category occurs frequently in the data. By occurring frequently it becomes a stable pattern and therefore frequently related to other categories
- The core category relates easily to other categories and the connections are frequent and can be clearly identified
- A core category in a substantive theory has implications for the development of a more formal theory
- As the details of the core category are analytically expanded the theory moves forward in development. The core category allows the researcher to build maximum variations from the analysis of data and to identify, for example, dimensions, properties, conditions, consequences, and strategies which relate to different sub patterns of the phenomenon referenced by the core category (p. 36) documents, code number of the participant, observations, date, and any other identification that enabled the researcher to easily retrieve the memo at a later date. Many of these memos were made during the stage of open coding as Strauss (1987) recommended that the researcher should ‘always interrupt coding or data recording for writing a memo, when an idea occurs, so that the idea is not lost’ (p. 127).

NVivo software facilitated this process allowing the development of concepts that related to a common theme grouped together. Concepts were then grouped and regrouped to find yet higher order commonalities called categories. It is these concepts and categories that led to the emergence of a theory. This process under which the theory developed evaluated the quality of a theory through detailed descriptions the data offers, the adoption of a systematic set of precise procedures for collection, analysis and refinement and the articulation of conceptually abstract theory. The researcher used the systematic comparison strategy proposed by Strauss and Corbin (1998). This involved comparing a phenomenon from one's experience or the research literature, with the data, in order to sensitise the researcher to the properties and dimensions of potential categories.

3.23 SAMPLING TECHNIQUES

Qualitative sampling was generally purposive or purposeful. LeCompte and Preissle (1993) used the term criterion-based sampling as the authors believe that qualitative researchers choose a certain criterion in advance as the study develops, theoretical sampling would be used to recruit participants who could provide data related to the emerging themes and categories (Morse, 2010). This helped to fine tune the focus of the study by testing ideas and views which have emerged with participants who have had relevant experiences (Holloway, 2009). The researcher ensured that a rigorous reflexive process was undertaken to mediate against her biasing in the theoretical sampling process. This included use of selection of participants and theoretical sampling that consisted of participants who were varied in age, ethnicity, NYHA, gender as part of the study to meet the research aims. These were purposively selected and extended accordingly.

All potential participants were provided with an information sheet about the study. Informed consent was sought in writing from each person and a cooling off period built in.

Entering the field where data collection took place was an overwhelming experience. A plethora of challenges took place. To illustrate the journey, key examples have been highlighted below:

- It became uncomfortable when patients hesitated in describing their experiences and gave minimal responses. The researcher found it challenging when trying to spark a conversation especially when patients gave one-word answers and held back in engaging in conversation.
- It was upsetting to hear of patients' poor quality of life and how the effects of a debilitating condition had impacted their lives, especially those who were affected by

the condition at a young age or those living alone and coping with living with the struggles of heart failure. It was also upsetting to hear the responses of family caregivers. For example, the excruciating pain and loss they felt of their loved ones suffering and the impact this was having on their own quality of lives.

- It was upsetting to see patients feeling helpless. However, at times, it was also inspiring to see the gratitude for life despite living with poor health.
- It was slightly uncomfortable, at times, when the male counterparts discussed their sexual activity status and the impact this had on their lives.
- Some patients were quite defensive of the researcher's presence and were reluctant to give information of their experiences of living with heart failure.
- The researcher felt helpless as patients looked to her for emotional support and/or occupational support; this was not something the researcher could help them with as it was outside the researcher's role.

3.24 THEORETICAL SENSITIVITY

According to Glaser and Strauss (1967), theoretical sensitivity is developed in the researcher over a period of time and they claimed that it had two major characteristics: 'first, it involves his personal temperamental bent and second, it involves the sociologist's ability to have theoretical insight into his area of research, combined with an ability to make something of his insights' (p. 46). Strauss and Corbin (1990) elaborated further that theoretical sensitivity referred to 'the attribute of having insight, the ability to give meaning to the data and dwell upon it, the capacity to understand, and capability to separate the pertinent from that which isn't' (p. 42). Theoretical sensitivity was essential in developing an informed framework (Glaser & Strauss, 1967). It required 'openness to the unexpected' (Charmaz, 2006, p. 136) which can spark sensitive insights into what the data is conveying (Locke, 2001). This in turn aided in raising analysis to more abstract levels whilst ensuring the emerging theory continued to resonate with participants.

Theoretical sensitivity described the researcher as sensitive to the important issues in the data (Holloway, 1997). The term was originally used by Glaser (1978) who believed that sensitivity assists the researchers in developing theories. Theoretical sensitivity derived from professional and personal experience and lent itself through knowledge of the relevant literature and interaction with and immersion in the data contributing to this awareness. Theoretical sampling has been a method of data collection based on concepts/themes derived from data. The purpose of theoretical sampling has been to collect data from places, people, and events that would maximise opportunities to develop concepts in terms of their properties and dimensions, uncover variations, and identify relationships between concepts (Corbin & Strauss, 2008).

As the study developed, theoretical sampling was used to recruit participants who provided data relating to the emerging themes and categories (Morse, 2010). This helped to fine tune the focus of the study by testing ideas and views which emerged with participants who had relevant experiences (Holloway, 2009). The researcher ensured that a rigorous reflexive process was undertaken to mediate against bias. This included selection of participants who varied in age, ethnicity, NYHA, and gender as part of the study to meet the research aims. A purposive sample was therefore selected and extended accordingly.

In this study, theoretical sensitivity was increased through increased self-awareness as well as acknowledging prior knowledge accumulated as a volunteer on the cardiac rehabilitation. In addition, time was spent by the researcher reflecting on her own assumptions about managing heart failure and the role of the family caregivers. Assumptions are statements considered to be true even though they have not been scientifically tested. According to Burns and Grove (1999), ‘assumptions are often embedded (unrecognised) in thinking and behaviour, and uncovering these assumptions requires introspection’ (p. 38).

The ability to recognise any assumptions or preconceived ideas was a strength which in turn led to rigorous development. Familiarisation with literature, in conjunction with meeting healthcare professionals and undertaking a volunteer placement highlighted the types of issues that could impact on the participant’s domestic, social, and leisure routine. Financial security, stability, personal and professional relationships, mental health coping and adjustment, and achievement of personal goals were acknowledged (Bernheim & Lehman, 1985; Zirul et al, 1989). In noting these preconceived ideas the researcher also observed that the majority of studies undertaken on caring and in the management of heart failure used quantitative methodologies and therefore these studies, which formed the basis of many of the researcher’s preconceived ideas, had not fully explored the multi-dimensional experience from the heart failure patients’ and family caregivers’ perspectives.

By using qualitative methodology, the researcher anticipated a more expansive understanding of the subject area. The researcher’s exposure to community cardiac rehabilitation was limited in duration; however, the researcher had sufficient exposure to facilitate acceptance and understanding of the culture and language and genders of the community setting.

Prior to commencing the first interview with a heart failure patient, the researcher made the following memo in a journal:

Today I am reflecting on what I believe it must be like to be a patient. It has become apparent that patients feel a sense of 'loss of role' and feel despair due their diagnosis. Heart failure patients lack ability to resume activities they once carried out prior to immobility and symptomatic disabilities. It is a frustrating and debilitating struggle to live on many levels including physical, emotional and mental. Inadequate resources leave patients feeling unequipped with knowledge of how to effectively self-manage without confusion and uncertainty and much misunderstanding. It is very upsetting to observe such poor quality of life.

Prior to commencing the first interview with a family caregiver, the researcher made the following memo in a journal:

I have had limited contact with family caregivers and families as a volunteer worker. I have had the opportunity to talk with family caregivers but only when they are attending clinic although each contact appeared sporadic a long-term relationship was established. I have established the strains of living with heart failure. Since I began to plan this study, I have thought about what it must be like to be a family caregiver. I have read quite a lot of literature over the years highlighting issues, such as, the burden of care, which is frequently mentioned. I presume it has some influence on finances, some effect on the family caregiver's health and leisure time. They may be unable to work because of the responsibilities of caring. Many people being cared for must live at home and this must have a disruptive influence on family life. I feel that family caregivers must get tired with all the worry and responsibility associated with the role.

During the course of this study, the researcher's assumptions and preconceived ideas were challenged and debated with colleagues at university as PhD qualitative analyses seminars were conducted every month. During presentations to the group, the assumptions, along with the findings of data analysis, were scrutinised by supervisors and colleagues (at no time during these discussions was participants' confidentiality compromised). Their feedback helped to clarify the overall methodological process and to avoid the imposition of researcher biases on the data. The meetings also facilitated theoretical sensitivity and opened data to new insights of meanings. In addition, the regular meetings with supervisors provided further mentorship and guidance in this area.

3.25 SATURATION

Glaser and Strauss (1967) viewed saturation as occurring when no additional data were collected that enabled the researcher to develop properties of the category (p. 61). They stated, ‘The criteria for determining saturation, then, are a combination of the empirical limits of the data, the integration and density of the theory, and the analysis’s theoretical sensitivity’ (p. 62). Strauss and Corbin (1990) suggested that if saturation was not achieved the grounded theory generated would be conceptually inadequate (Holloway, 1997). In this study, sampling continued until saturation, or the failure to obtain new information for all identified categories.

The processes of data collection, analysis, constant comparison, memo writing, and theoretical sampling continued in an iterative cycle. Ideally recruitment of participants would stop at the point when no new concepts emerged from interviews and key elements were repeating; this would define the sample size (Corbin & Strauss, 2008). It was emphasised that the intention was to achieve saturation, although Bluff (2005) argued that it was never possible to state this categorically. It was, however, acknowledged that because this was a time limited study there was the possibility that saturation may not be fully achieved, and that theory development might be incomplete. Furthermore, knowing when this point had been achieved was difficult, since every new case might provide a new theme or require modification of existing categories, at least to some degree (Seale, 1999). Recruitment of participants stopped at the point when no new concepts emerged from interviews and key elements repeated: this defined the final sample size (Corbin & Strauss, 2008). Once validation of the theory had been achieved, the recruitment of further participants became redundant. In view of the limited time to collect and analyse data, eighteen were carried out to achieve theoretical saturation.

A purposive approach to sampling was adopted in order to include a diverse group of patients (for example different ages, socio-economic backgrounds, and gender); this was informed by the literature review.

Data generated through these interviews were analysed using the constant comparative method. This entailed close reading of transcripts and an iterative process of developing thematic categories. Initially, open codes were generated to begin to categorise the data and produce a preliminary coding frame. NVivo version 10 software was then used to organise the data into this coding frame, which was continually evaluated, refined and added to as necessary throughout the process. The main premise of the approach was that theory emerged from, and was grounded in, the data. The honing of theory by this constant comparison process continued until a level of saturation was reached and emergent categories emerged.

Grounded theory has an inductive approach, data analysis and data phases of the project proceed simultaneously. The analytic process has prompted theory discovery and development as opposed to verifying pre-existing theories. Theoretical sampling has refined, elaborated and exhausted conceptual categories (extending ideas and sampling of population). The systematic application of grounded theory analytic methods would progressively lead to more abstract analytical/theoretical levels (Charmaz, 1983).

Data analysis began at the same time as data collection, since it was used to direct further data collection through a series of sequential or interim analyses (Charmaz, 2006; Mays et al, 2000). It was therefore an integral part of the research process and not an activity that only occurred after data collection (Charmaz, 2006). The process of analysis was meant to ensure that the findings of a study were ‘grounded’ in the data (Glaser & Strauss, 1967).

Grounded theory, as a product of its time, originally referred to an account of the concept of rigour that included validity and reliability, which may not adequately address reflexive concerns (Hall & Callery, 2001). Charmaz (2006) argued that in the practical application in qualitative research, grounded theory may be best viewed as a ‘set of principles and practices, not as prescriptions or packages’. Barbour (2003) pointed out that it was unlikely that anyone used it in its pure or original form and that:

‘Grounded theory is also invoked as a distinct philosophical approach to qualitative research. This can, however, obscure or de-emphasise its practical application. Used in this way grounded theory allows for theory generation, and its strength lies precisely in its non-partisan character, that is, it is amenable to very different and potentially contradictory theoretical paradigms.’ (Barbour, 2003).

Similarly, Seale (1999) argued that ‘qualitative researchers would benefit from retaining a hold on the underlying principles of grounded theorizing, rather than dismissing these as inconsistent with modern sensibilities’ since:

‘Although grounded theory emerged in an era of scientism, and it’s more technical explications are sometimes unwelcome reminders of this, the spirit that lies behind the approach can be simply explained and does not have to be attached to a naively realist epistemology, or indeed to an oppressive urge to force readers to regard its products as true for all time. It demands a rigorous spirit of self-awareness and self-criticism, as well as an openness to new ideas that is often a hallmark of research studies of good quality’ (Seale, 1999).

With these points in mind, the practical approach to this study described the broad principles of grounded theory. This meant that the techniques of constant comparison, deviant case analysis and theoretical sampling were used in order to ground the findings in the data.

During the initial stages of the recruitment process, the uptake of participants was slow. However, with the support of the heart failure and community heart failure nurses who aided the introduction of the researcher's role and requirements, the process of further recruitment proved to be successful to the study.

The aim of grounded theory approaches was to continue to recruit and interview participants until no new categories emerge, at which point saturation was achieved. In these initial stages of the study, thirteen interviews were conducted with no new categories emerging that related to the topics in the interview guide. This was later confirmed by the final five interviews.

The researcher believed she had a relatively good understanding of the data, the process of analysis and the iterative process of the phases of the study provided insights into the grounded theory process. There were periods of times where her thinking lacked flexibility and perhaps this hindered creative insights. However, through consultation discussions with her supervisory teams the rigidness became more flexible and she strived to achieve an understanding using grounded theory principles and adopted a more dynamic outlook as opposed to being linear. The researcher spent considerable time discussing saturation. The researcher began to realise, with supervisory input, the subjective nature of this decision and referred to the process of checking data to un-cover new data. The researcher did not want to reach saturation prematurely and thereby miss out on new open codes. Therefore, The researcher continued to organise the open codes through the constant comparison process. The researcher documented further saturation checks. The researcher revisited the raw data to maintain a sense of familiarity and connectivity with the data. The researcher re-read transcripts, memos and codes; and concluded that saturation was approaching where no new ideas were being generated from the interviews, in line with Strauss and Corbin:

'Saturation is more a matter of reaching the point in the research where collecting additional data seems counterproductive; the 'new' that is uncovered does not add that much more to the explanation at this time' (Strauss & Corbin, 1998, p. 136).

The researcher revisited raw data on numerous occasions following supervisory advice, this included listening back to interviews in addition to interview transcripts and observational notes. This proved fruitful, as the similarities and differences contained in interviews between transcripts highlighted comparisons which challenged emerging ideas leading to the revelation of important codes. This tightened up the parameter of the codes enabling more focused coding identifying and assigning supporting quotes for this. Strauss & Corbin (1998) described a technique called 'Waving the Red Flag' to challenge assumptions. The researcher employed this technique in her memos.

The decision to cease recruitment was made because it was felt that saturation had been achieved. However, knowing when this has been achieved was difficult, since every new case might provide a new theme or require modification of existing categories (Seale, 1999). In this stage a difficult issue related to the under representation of women in the sample (five females), which seemed to reflect the under-representation of women in the cardiac rehabilitation programme more generally, rather than there being a greater proportion of women than men choosing not to participate. However, significant gender differences in patients' perspectives did not seem to be apparent in the data, which was why the decision was made to cease recruitment.

In the second phase of the study the intention was to re-interview patients post a 12-week period to explore life post the initial discharge period and the adaptation to living with heart failure especially concerning whether patients' experiences had changed over time and, if so, to ascertain whether this had affected their perspectives of daily management. Four patients did not part-take within the second phase.

It was recognised that claiming saturation was reached in this stage of the study could be questioned on the grounds that further recruitment of patients would have been extremely difficult, which might have led to a premature claim of saturation. However, less variation in perspectives was noted between patients than in the initial stage and no major new categories appeared to be emerging that related to the topics in the interview guide by the ninth interview or after. The decision not to recruit further patients was made on this basis, although deciding whether saturation was actually achieved remained a difficult issue.

The third stage of the study involved interviews with family caregivers of patients. The decision to cease recruitment at this point was made on this basis that by the time eight or nine interviews had been conducted no new categories appeared to be emerging that related to the topics in the interview guide, which was confirmed by the remaining three or four interviews. At this point it was felt that saturation had been reached (O'Reilly et al, 2012).

The fourth phase of the study involved focus group discussion with eight healthcare professionals. Saturation had been achieved when no new information was emerging that related to the topic guide. The researcher strongly believed the discussions led by healthcare professionals elicited strong viewpoints that related to the topic guide, allowing rich data to emerge.

The researcher was confident at this stage that the process of saturation was in reach as a real grasp of the data was at completeness with most of the codes appearing to 'fit' within the emerging framework of codes, indicating a good level of consistency.

A basic grouping of categories and concepts started to emerge aiding the process of refining and development of the properties and dimensions of the major categories. The researcher reviewed the data associated with the open codes; The researcher used Strauss and Corbin's (1998) conditional/consequential matrix as a framework for sorting through the different properties. This helped the researcher to understand that some of the data was part of the context in which action took place, with its ensuing consequences. The researcher started to identify the properties from the data and the dimensions associated with different phenomena.

Strauss and Corbin (1998) described how the analysis carried on into write-up. The researcher continued to make sense of the data as she wrote using selective quotes which supported her explanation of the categories. This process helped her to identify the sub-categories. The emergence of a core category did not simultaneously arise, several discussions with the supervisory team about the interview storylines and sub-categories and especially the need to avoid a static linear fashion of depiction of the processes of categories which explored explanations was imperative for the researcher's struggle to identify a core category/categories.

Data analysis therefore progressed through various levels of coding and became more abstract as a theoretical framework emerged (Corbin, 2009). Charmaz (2006) suggested that it was a flexible and adaptable process in which analytical ideas were brought together to develop a conceptual framework. The ideas and themes which emerged from the data were identified and these generated new ideas to be followed up in subsequent interviews. The schedule of questions was adapted to reflect these (Wimpenny & Gass, 2000). This was as an ongoing process to elicit rich data. The theoretical framework was gradually built as codes were attributed to the actions and processes identified in the data. Links between codes were established as coding became further focussed; restructuring data by specifying potential relationships began to explain larger segments incorporating a higher level of abstract categories (Locke, 2001).

3.26 BRACKETING RESEARCHER BIAS

A hallmark of qualitative research has been the researcher's emphasis on open mindedness and curiosity (Chenail, 2000). Sword (1999), in contrast, indicated that some qualitative researchers 'do not acknowledge how, among other things, their own background, gender, social class, ethnicity, values, and beliefs affect the emergent construction of reality' (p. 270). This was further supported by Rose and Webb (1998) who claimed that 'not only the research process' but also the researcher's effect on the research process and 'vice versa' was relevant (p. 559).

Throughout this study, the researcher reflected on how their personality and knowledge of the subject area might bias, impact or compound research outcomes.

There were some streams of thought within grounded theory that advised against contact with the literature (Glaser & Holton, 2004). The researcher approached literature with caution; it was not possible to go into the study blind. The researcher had undertaken a volunteer position at a cardiac rehabilitation trust within the West Midlands, prior to the study. In addition, the researcher had also undertaken an employment research post within coronary heart disease, which meant the researcher had both experience and knowledge both theoretically and in practice. Moreover, the researcher had read much literature to develop a PhD proposal and ethics applications for both the NHS and university.

Furthermore, the researcher sought the advice of her supervisors which was to read literature more broadly around the various aspects of the study and there were times when my supervisors guided towards relevant literature after a discussion of emerging concepts related to my study. Thus, the researcher tried to maintain neither a balanced approach of neither full immersion nor lack of contact. The researcher continued to make memos in which she described and reflected on experiences that affected her and facilitated transparency and developed self-awareness of substantial influences. In doing this, during the analysis, the researcher sought to be grounded in the data.

The ten tips outlined by Ahern (1999) to enhance reflexivity and the researcher’s ability to bracket these were useful in this process. They gave structure to self-evaluation and journaling that covered:

- Interest and personal issues that led to completing this research were documented.
- Value system and areas of subjectivity that could influence the researcher’s ability to conduct the research.
- Areas of conflict that may influence the researcher’s ability to complete the research.
- Problems with gatekeepers and how these were managed.
- Feelings that might compromise the researcher’s neutrality.
- Ability to recognise if there is anything new or surprising in data collection. If not, is this a concern or does it indicate saturation.
- Problems and blocks that occurred during the research and the questions asked to identify what was happening.
- Reflection on the procedure of writing up the findings when data analysis was completed.

- Ability to identify if the substantive literature review was supportive of the results of the study or whether it was just expressing the same cultural background as the researcher; and
- Ability to deal with any bias, for example, a script may need to be re-analysed if it was identified that bias had occurred during the analysis (Ahern, 1999).

In practice, the above framework was used throughout all aspects of this study. The suggestions supported the study in practice at separate intervals. Supervision consultations were arranged to displace measures of personal biases and a conscious effort was made to discuss transcripts at length whilst making reference to a reflexive journal; this was particularly useful in developing the researcher's theoretical sensitivity and in identifying issues that could affect researcher neutrality. The framework acted as an aid to solve problems encountered during the study as they arose. Identification of arising issues allowed the opportunity to intervene and re-direct the chain to meet the needs of the study, when deemed appropriate.

3.27 RESEARCHER EFFECT

The qualitative researcher's perspective has been perhaps a paradoxical one: it was to be acutely tuned-in to the experiences and meaning systems of others—to indwell—and at the same time to be aware of how one's own biases and preconceptions might be influencing what one is trying to understand (Rager, 2005).

Adler and Adler (1987) identified three 'membership roles' of qualitative researchers engaged in observational methods: (a) peripheral member researchers, who did not participate in the core activities of group members; (b) active member researchers, who became involved with the central activities of the group without fully committing themselves to the members' values and goals; and (c) complete member researchers, who were already members of the group or who became fully affiliated during the course of the research.

Being an insider helped develop an understanding for the journey that Pakistani heart failure patients and their family caregivers experienced. The researcher realised she sometimes shared experiences, opinions, and perspectives with participants, and at other times (I) she did not. It was not that the researcher sometimes saw herself as an outsider instead of an insider. Rather, not all populations are homogeneous, so differences were to be expected.

Being an outsider to chronic heart failure and related co-morbidities, the researcher shared no experience of chronic illness. The majority of the participants in the research did not seem to perceive this as an impediment to the research process. In one instance a male heart failure patient did express concern of my 'outsider' status and questioned my capacity to appreciate fully their experiences. The researcher acknowledged and respected his view but that it was the researcher’s hope to learn from the participants and their experiences so that she and others might gain insight into their management and its impact.

Nevertheless, interviews proceeded, and much meaningful information was shared. Although the researcher’s membership status in relation to the participants did not seem to affect the interviews negatively, it raised an important point that must be considered in all research endeavours with participants who identify with a group based on shared experience, gender, sexuality, ethnicity, race, and so on. This issue has confronted both researchers who are members of the group they are studying and those who are not, for there are costs and benefits to each status.

There appeared to be as many arguments for outsider research as against (Serrant-Green, 2002, p. 38). For each of the ways that being an insider researcher enhanced the depth and breadth of understanding a population that may not be accessible to a non-native scientist, questions about objectivity, reflexivity, and authenticity of a research project were raised because perhaps one knows too much or is too close to the project and may be too similar to those being studied (Kanuha, 2000, p. 444).

Insider research has referred to when researchers conduct research with populations of which they were also members (Kanuha, 2000) so that the researcher shared an identity, language, and experiential base with the study participants (Asselin, 2003). The complete membership role gave researchers a certain amount of legitimacy and/or stigma (Adler & Adler, 1987). This insider role status frequently allowed researchers more rapid and more complete acceptance by their participants. Therefore, participants were typically more open with researchers so that there might be a greater depth to the data gathered. Talbot (1998-1999) noted this phenomenon in her study of mothers who had experienced the death of an only child. She wrote, ‘At the end of their interviews, several mothers said they would never have shared certain aspects of their experience if I had not been a bereaved mother also’ (Talbot, 1998-1999, p. 172). The stigma referred to the view of outsiders, who might see this role as creating a heightened level of researcher subjectivity that might be detrimental to data analysis and even collection. Adler and Adler (1987) asserted that the distinction between researcher and participant has ‘traditionally existed more strongly in theory than in practice’ and that ‘objectification of the self has occurred in the analysis rather than the fieldwork’ (p. 85).

Although emphasis on ‘objective’ data had been replaced with focusing on the advantages of subjective aspects of the research process (Adler, 1990) being an insider was not without its potential problems. In Adler and Adler’s (1987) discussion of complete member researchers, they suggested that in this ‘ultimate existential dual role’ (p. 73), researchers might struggle with role conflict if they found themselves caught between ‘loyalty tugs’ and ‘behavioural claims’ (Brannick & Coghlan, 2007, p. 70). Asselin (2003) has pointed out that the dual role can also result in role confusion when the researcher responded to the participants or analysed the data from a perspective other than that of researcher. The author observed that role confusion could occur in any research study but noted that there was a higher risk when the researcher was familiar with the research setting or participants through a role other than that of researcher.

The benefit to being a member of the group one was studying was acceptance. One’s membership automatically provided a level of trust and openness in participants that would most likely not have been present otherwise. One had a starting point (the commonality) that afforded access into groups that might otherwise be closed to ‘outsiders’. Participants might be more willing to share their experiences because there was an assumption of understanding and an assumption of shared distinctiveness; it was as if they felt, ‘You are one of us and it is us versus them (those on the outside who don’t understand).’

Although this shared status could be very beneficial as it afforded access, entry, and a common ground from which to begin the research, it had the potential to impede the research process as it progressed. It was possible that the participant would make assumptions of similarity and therefore fail to explain their individual experience fully. It was also possible that the researcher’s perceptions might be clouded by his or her personal experience and that, as a member of the group, he or she would have difficulty separating it from that of the participants. This might result in an interview that was shaped and guided by the core aspects of the researcher’s experience and not the participants’. Furthermore, its undue influence might affect the analysis, leading to an emphasis on shared factors between the researcher and the participants and a de-emphasis on factors that are discrepant, or vice versa (Watson, 1999; Armstrong, 2001). Here, the authors reported that without being a member of the group under study, their research would have been problematic if not near impossible.

Despite this important benefit of being a member of the group studied, there were also drawbacks; both Watson (1999) and Armstrong (2001) acknowledged a lack of clarity stating: ‘I still remain unclear whether this is my interpretation of an actual phenomenon, or if I am projecting my own need . . . onto my participants’.

It was clear there were costs and benefits to be weighed regarding the insider versus the outsider status of the researcher. Being an insider might raise issues of undue influence of the researcher’s perspective but being an outsider did not create immunity to the influence of personal perspective. Furthermore, although there might have been caveats to being a member of the group studied, for many access to the group would not have been possible if the researcher was not a member of that group. The positive and negative elements of each must therefore be carefully assessed. Being a member of the group under investigation did not unduly influence the process in a negative way. Disciplined bracketing and detailed reflection on the subjective research process, with a close awareness of one's own personal biases and perspectives, might well reduce the potential concerns associated with insider membership. Furthermore, one did not have to be a member of the group being studied to appreciate and adequately represent the experience of the participants. Instead, the core ingredient was not insider or outsider status but an ability to be open, authentic, honest, deeply interested in the experience of one's research participants, and committed to accurately and adequately representing their experience (Fay, 1996).

The Space Between

The notion of the space between challenged the dichotomy of insider versus outsider status. To present these concepts in a dualistic manner was overly simplistic. It was restrictive to lock into a notion that emphasizes either/or, one or the other, you are in or you are out. Rather, a dialectical approach allowed the preservation of the complexity of similarities and differences. 'In a dialectical approach, differences are not conceived as absolute, and consequently the relation between them is not one of utter antagonism' (Fay, 1996, p. 224). Although a researcher's knowledge was always based on his or her positionality (Mullings, 1999), there was an appreciation for the fluidity and multi-layered complexity of human experience. Holding membership in a group did not denote complete sameness within that group. Likewise, not being a member of a group did not denote complete difference. It seemed paradoxical, then, that any endorsement to binary alternatives that unduly narrowed the range of understanding and experience would occur. To be considered the same or different required reference to another person or group. Fay (1996) noted that each required the other: 'There is no self-understanding without other-understanding' (p. 241). This was the origin of the space between. It was this foundation that allowed the position of both insider and outsider (Adler and Adler, 1994). As a researcher, which, depending on one's perspective, she found herself occupying this space between the two perspectives which afforded a deeper knowledge of the experiences being studied both from patient and family caregiver perspectives.

There was a possibility that the presence of the researcher of the same cultural background might affect the heart failure patients' and family caregivers' responses and behaviour. There was the potential that the development of a rapport with participants, as a result of a shared understanding of language and culture, may have led participants to feel that they had to behave in a certain manner. Participants might have perceptions of the researcher's expectations and hence feel the need to fulfil these. Consideration was given to this and attempts were made to minimise the effects. Conversely, the shared cultural background between the researcher and participants and language similarities could affect the researcher's expectations. The researcher was aware and conscious of this throughout the study. A reflective journal was kept of any behaviour changes in relation to this.

The researcher's capacity as insider supported her research with several advantages. The researcher was able to be a part of a culture that lent itself strongly to the population she was studying. The similarities she shared were:

- Religion: The researcher too was a Muslim; therefore, Islam was a faith all (her participants shared.
- Culture: The researcher was too was in origin Pakistani. The researcher was from a shared culture which brought together common ground for understanding norms and values of Pakistani citizens.
- Language: The researcher spoke fluently and understood Urdu, Punjabi and English in which her participants communicated.
- Same gender: helped female participants to discuss their experiences, issues and concerns more comfortably.
- Volunteer placement: The researcher undertook a volunteer placement prior to her research study, which gave insight into the types of cardiac rehabilitation classes and programmes (see Appendices 11.8). This aided a better understanding of cardiac rehabilitation, types of patient issues and protocol.
- Knowledge: of cardiac programme and knowledge of HF condition.
- Living with a severely poorly patient in her personal life and, at times, acting as a family caregiver provided skills which built the foundations of empathy when carrying out interviews with patients and family caregivers.

Communication with female participants was better reciprocated as being female herself eased the population establishing good rapport. It was hoped the study would give both patients and family caregivers the opportunity to express their real concerns whilst feeling at ease with the researcher to discuss openly barriers they faced whilst managing their chronic condition, thus providing rich contextual data emphasising potential gaps for improvement.

However, being of the same background, disadvantages that impinged on the study might have included the following:

- Cultural similarity might hinder participants from engaging fully in the interview as they might feel that certain topics of concern had a shared understanding, thus not having the need to fully explain and be explorative with detailed conversation.

- Being the opposite gender might deter male participants from discussing their condition as they might feel uncomfortable talking about certain sensitive private matters.
- Lack of awareness of specific medical education that both patients and family caregivers might expect to be answered by the researcher. It was anticipated that this would be overcome by directing them to their health care professional member to discuss their condition in further detail.
- Intimidated by professional role, therefore not disclosing certain home remedies or treatment methods that had been adopted via hearsay or cultural traditions and norms.

However, a disadvantage of researcher effect was that assumptions of the participants' world could be made which might hinder data collection. Participant behaviour might change as a result of being someone who was from the same ethnic group making them too relaxed and not deeming the study professional assuming that explanations of certain behaviours are a 'norm' and that presence was informal. This might potentially allow participants to not disclose information that was important.

As an outsider, having no personal medical history of heart failure or related chronic disease, the researcher was partially able to empathise how much distress was being experienced through personal experience of living with a loved one who resembled symptoms of the participants. The researcher was not in the same 'club' as the patients who were going through their challenges; she was looking through a glasshouse. The researcher I would never know the true extent of what it meant to be living with heart failure both as a patient and family caregiver. However, the researcher believed that having 'insider qualities' helped in the process of carrying out interviews as they supported my role as a researcher.

The researcher's experience extended via her father who was a former patient of dialysis (three, four-hour weekly sessions). Recently he was gifted a kidney from a donor. However, this was not without its complications. The researcher's father post his kidney transplant developed complications; sepsis and E-Coli infections. This was partially due to his immunity suppressed at the point of surgery making him susceptible to infection and also that the kidney had not 'woken' up and so was due to the lack of dialysis and kidney not functioning immediately or with the use of steroids, urea levels caused the toxins to raise leading to delirium and a heart attack. Consequently, a mass of medications was administered, blood transfusions and a NG feeding tube. The delirium life-threatening as the imbalance of chemicals in the body led to the possibility of mortality and this fact was frightening. After a lengthy admission in hospital, events changed, leading to recovery with the donor kidney functioning.

Nevertheless, post the experience another admission to hospital relating to renal issues, sadly a diagnosis of cancer in the liver was pronounced, again a testing time and numerous examinations led to surgery. As a family caregiver it was a very difficult time for all members of the family, both through admission stage and post discharge as recovery was an on-going process which brought challenges with both the patient (father) and health professional members when accessing services.

Furthermore, the researcher’s mother-in-law who had been a long-term vascular dementia patient with 24-hour home care was strictly bed and wheelchair bound with all her medical and personal care looked after due to complete immobility. The researcher had seen the challenges of living with dementia and dialysis (both chronic conditions disabling in different ways) from both a patient and family caregiver perspective. It bears enormous emotional, physical and mental strain, much of what had been depicted in this research.

3.28 COMPARISON WITH EXISTING LITERATURE

The final stage of data analysis consisted of comparing the findings of this study with related or relevant existing theories already reported in scientific literature. When using grounded theory this comparison with existing literature was carried out at the end rather than the beginning of the research process (Glaser, 1978a). This approach minimises the risk of the imposition of preconceived ideas on data analysis. Comparing the substantive theory developed in this study involved critically reviewing theories identified in the literature as potentially having relevance to the newly developed theory. Those that were found to be related to some of the theoretical constructs identified in this study were considered in depth.

3.29 WRITING THE GROUNDED THEORY

Upon reaching saturation and the basic social psychological problem and processes, the journey of documenting a framework of the patient and caregivers’ experience managing the unique heart failure experience of rehabilitation emerged. Data that had been broken down post interviews during open coding process and developed through theoretical and selective coding, along with the many theoretical memos, were now documented as the emerging substantive theory.

In writing this thesis a high proportion of direct quotes from participant interviews have been included thus providing ‘thick rich descriptions’. Inclusion of this data assisted the researcher to descriptively explain variations of concepts (Bradbury-Jones, 2007). Using undiluted quotes provided participants with a voice, which had not been altered by researcher bias.

Therefore, the words used by participants have not been changed in any way. Denzin and Lincoln (1994) supported this, asserting that ‘the intent is to create the conditions that will allow the reader, through the writer, to converse with (and observe) those who have been studied’ (p. 506). In documenting the information obtained from participants in this study the following procedure was followed:

- For each quote by a participant documented in this study the participant’s code number is recorded, for example, MH.
- For each field note the number and date are recorded.
- For each memo the number and date are recorded.
- Major conceptual terms used in the substantive theory were placed in italics.
- Square brackets [ ] were used in direct quotes when additional information was added by the researcher.
- Pseudonyms and asterisks * were used in the quotes from participants to protect the identity of the participants, people identified by participants during the interview, and the names of hospitals or health services.

According to Morse (1999), qualitative findings can be generalized, and the knowledge gained is:

‘ … not limited to demographic variables; it is the fit of the topic or the comparability of the problem that is of concern. Recall it is the knowledge that is generalized. Once qualitative researcher recognize [sic] that qualitative findings are generalisable, [sic] qualitative research will be considered appropriately and more useful, more powerful, and more significant’ (p.6).

In this study, the trustworthiness, credibility, and transferability of data were primarily assured by following the detailed methodological processes of grounded theory method. According to Glaser and Strauss (1967) this process involved ‘(1) comparing incidents applicable to each category, (2) integrating and their properties, (3) delimiting the theory, and (4) writing the theory’ (p.105). Using grounded theory methodology, data analysis began at descriptive level whereby an individual participant’s experience of caring for a person with chronic heart failure in the Midlands’ community was coded and categorised. Coding then progressed to conceptual level, whereby comparisons were made between patterns of social responses to the phenomenon.

Data analysis included the use of theoretical memos about data driven ideas and questions regarding codes, hypotheses, categories and the evolving grounded theory. From this process, the basic social psychological problem experienced by participants and their response to that problem were identified. Using Glaser and Strauss’s (1967) grounded theory method, the coding process completed in this study was not linear, in that although the analysis progressed through three coding stages, coding methods continued to overlap and early coding practices continued to be used throughout the process.

3.30 TRUSTWORTHINESS, CREDIBILITY, AND TRANSFERABILITY OF FINDINGS

Establishing trustworthiness, credibility, and transferability of data has been an essential step in qualitative research (Rose & Webb, 1998). Particular requirements of grounded theory methodology which relate to trustworthiness, credibility, and transferability of findings are that: the theory fits the substantive area where it would be applied; it was understood by those who could use it, and in general, it was applicable to different situations and provided those who use it with some control over changes in daily situations (Glaser & Strauss, 1967).

The sampling strategies used in this study ensured that the experience described by participants was the experience of the population in this study area and that the data were saturated, comprehensive, complete, and accounted for negative cases. The credibility of the findings was supported by accounts of similar experiences by the majority of participants. Recurrent patterning of responses from participants also added to the trustworthiness of the findings and these similar patterns of experiences became more evident as the stages and phases of the substantive theory emerged.

The credibility and trustworthiness of the findings in this study also contributed to the transferability of the findings and the substantive developed theory. This might be applied to participants in other geographical areas enduring similar illnesses (Glaser, 1978). There was considerable discussion regarding what constituted an audit trail in qualitative research literature with some authors stating that too rigorous demands on the researcher to document audit trails might impinge on the creative processes fundamental to qualitative research (Sandelowski, 1993). Rodgers & Cowles (1993) claimed that there was confusion regarding what researchers needed to demonstrate in an audit trail. They described four types of documentation that should be presented as part of all qualitative research and these were followed in this study:

- Contextual documentation, (field notes).
- Methodological documentation, such as, changes to interview questions based on data analysis and clear descriptions of the methods used, for example, theoretical sampling decisions.

- Analytical documentation, for instance, the identification of conceptual links in the emerging data, and
- Personal response documents of ongoing reflexive self-awareness notes by the researcher throughout the process of analysis.

This was later reiterated (Rodgers & Cowles, 1993; Guba & Lincoln, 1988). Another way trustworthiness, credibility, and transferability of the findings were ensured, was to review the findings with participants as well as other people who had experience in the phenomenon under study (part of the theoretical sampling procedures used in this study). Therefore, the eighteen heart failure patients in this study were re-interviewed to help to clarify and/or further explore concepts identified in their original interviews. Their confirmation of the conceptual theory reflected their experiences fortifying the trustworthiness, credibility, and transferability of data. It ensured a wide perspective of experiences of the phenomenon under exploration. Using theoretical sampling to broaden the sample population, constant comparative analysis further ensured trustworthiness.

This allowed the validation and expansion of key concepts identified by the initial sample group. In addition, the findings of the study were presented to nine family caregivers who accurately affirmed that the substantive theory presented to them was an accurate representation of their caregiving experience.

The researcher met once a month with other students undertaking PhD studies using the grounded theory method. The discussion and feedback from these forums provided support for the trustworthiness, credibility and transferability of findings. In addition, the researcher completed all transcriptions of interviews to further reduce the chance of misinterpretation and mistakes being made (Easton et al, 2000) and direct quotes from participants have been included to allow the reader to ‘personally’ observe what has been studied. These steps further enhanced the trustworthiness, credibility, and transferability of the findings of the study.

Finally, the substantive theory of seeking balance to overcome being consumed was compared to the existing literature on self-managing chronic illnesses and caregiving. This literature was presented throughout this thesis and added to the credibility, trustworthiness, and transferability of the data and validation of the findings of this study.

In summary, detailed descriptions of the research process, the identification of an audit trail, linkages between data and observational notes and comparisons with existing literature on living with chronic heart failure and caregiving, facilitated the trustworthiness, credibility, and transferability of the findings nationally and internationally. The findings also provided the basis for further development and refinement of theory through studies in different contexts.

3.31 DATA STORAGE, ACCESS, AND DISPOSAL

All interviews, field notes, and reflective notes were coded and anonymised to prevent the identification of any participant. The codebook containing participants' names was safely kept in a locked cupboard separate from the transcribed interviews and audiotapes. Transcribed data was stored in a locked cupboard in the researcher's office for a period of five years following the completion of the study. After five years data would be destroyed. Any written publications resulting from this research will maintain the confidentiality of participants. Extracts from the interview transcripts might be published, but no identification to the source will be made.

3.32 RIGOUR

It is important that procedures used in this study were systematic and explicit. However, it was difficult to reproduce exactly a qualitative study because the context and original situation were unique. Therefore, it was essential that the study has coherence, consistency and flexibility (Byrne-Armstrong et al, 2001). In order to check for accuracy of representation and resonance each participant was given the opportunity to view and comment on the transcript of their interview. Any further comments participants liked to add at this stage were accepted as part of the data, but it was made explicit that these were not part of the original interview (Ryan & Griffith, 2010). Credibility was tested by returning the interpretations and findings of the study to participants to determine if they recognised their own experiences in these and that the study was compatible with their perceptions (Guba & Lincoln, 1989). Dependability too was achieved by inviting research supervisors to examine and categorise the data independently and then compare this with the primary researcher's analysis for congruence (Holloway, 2009). A clear audit trail was made available through the researcher's memos and fieldwork diary. Reflexivity in which the researcher continuously considered how she positioned herself in the study and the influences this might have on emergence of concepts was crucial in generating a transparent study (Galvin, 2009). The researcher aimed to ensure credibility, trustworthiness and authenticity of the findings (Holloway & Todres, 2003).

3.33 SUPERVISION CONSULTATIONS

Numerous consultation discussions were exchanged between the researcher and the supervisory team, which supported the study's needs.

Prior to commencing the PhD, the researcher brought a mind-set that heavily gave focus to the clinical and physiological aspects of heart failure; the researcher's approach was very clinical. However, the researcher's pattern of thinking shifted after discussions with her supervision team to thinking more about culture, and the lived reality of participants. This definitely progressed her role as a researcher.

In particular, a sociological perspective was expertly shared which emphasised and encouraged thinking in-depth about the population under study as opposed to HF and coronary heart disease, making the physiological disease secondary to the Pakistani individual. The perspective of the rehabilitation programme outside the physical condition was encouraged so that the perceptions of patients and their family caregivers' experiences were central to the study. This aspect of the discussion specifically honed in on the importance of the study's needs making it valuable in both its growth and contribution of new knowledge.

Thinking in this way, factors eliciting the cultural aspects of the lived experiences of the Pakistani population and how this embedded itself into the daily practice of self-management were brought to the forefront moving away from the physiological needs of cardiac rehabilitation and diagnosis of disease. By this, richness of data presented itself adding much value to the study, the researcher's understanding, creativity and knowledge.

3.34 SUMMARY OF CHAPTER

This chapter has represented a robust defence of the processes the researcher followed. It has offered an exploration of the key decisions I made and the development through the research process. The researcher has drawn on several source documents, namely supervisory consultation records and memos. The researcher carried out a personal account to contextualise her position both as an individual and as a researcher. The researcher systematically outlined my approach to data collection and described how she used the interview schedule. In addition, the researcher provided an account of how she developed as a researcher. This reflexive account was a further attempt to offer some context to the study through explaining how the researcher as an individual not remained static but has changed in her thinking with the support of her supervisory team. In the section on the initial data analysis the researcher chronologically and methodically presented the processes she followed, along with the emerging concepts in the data. The researcher demonstrated how she drew on grounded theory principles in the analysis and revealed how she used computer software to conduct the analysis (NVivo). Furthermore, she drew on extracts and diagrams from her journal to evidence the development of her thinking. As the researcher discussed the saturation decision, she has provided documentation to support this process and described in-depth the final process of the analysis which developed the core categories in detail.

The next chapter will demonstrate how these categories emerged from the data and how these categories were categorised and integrated to describe and explain emergent themes. The findings of the data analysis will explore the implications for addressing the needs of Pakistani heart failure patients and their family caregivers that reflect the perceptions of patients, in addition to highlighting the perceptions of healthcare professionals through focus group discussions.

4 CHAPTER FOUR: FINDINGS – PHASE 1 & 2

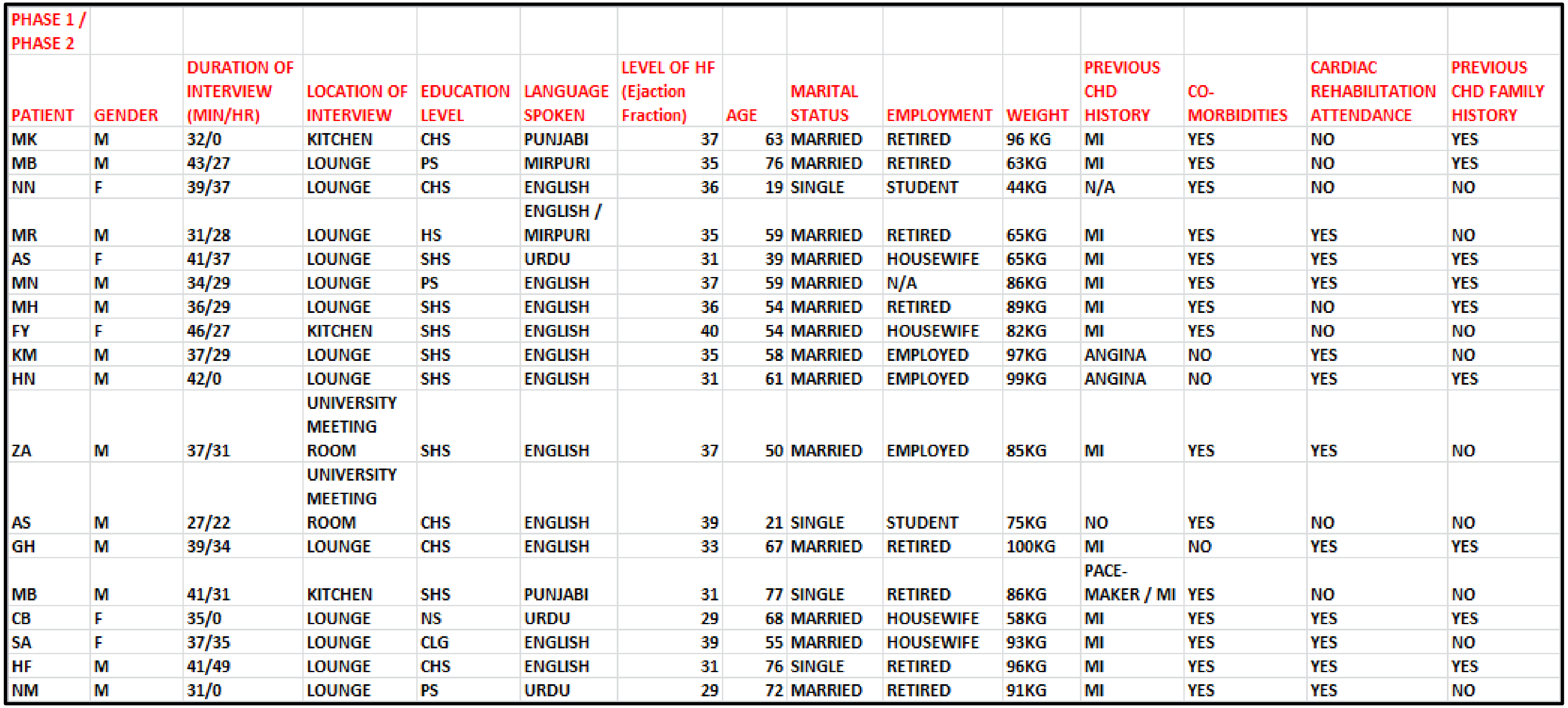
Chapters four, five and six illuminate the findings of the present study. These chapters demonstrate how the categories emerged from the data and how these categories were integrated to describe and explain the emerging grounded theory. The findings of the data analysis explore the implications for addressing the needs of Pakistani heart failure patients and their family caregivers. Furthermore, identification of the research outcomes is explored.

Phase 1 of the study explores patients who were interviewed to share their experiences of living with heart failure, consequently, this chapter initially describes two phases that reflect the perceptions of patients across a time continuum: immediately post discharge and at recovery phase (post 12 weeks).

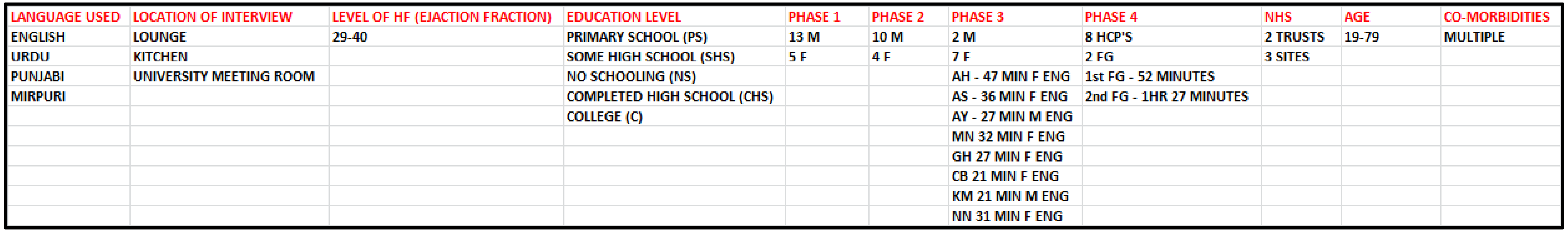
Phase 3 shares the experiences of family caregivers living with heart failure.

Phase four understands the perceptions and concerns of healthcare professionals through focus group discussions.

A basic demographic table is illustrated below which provides an overview of participant data:



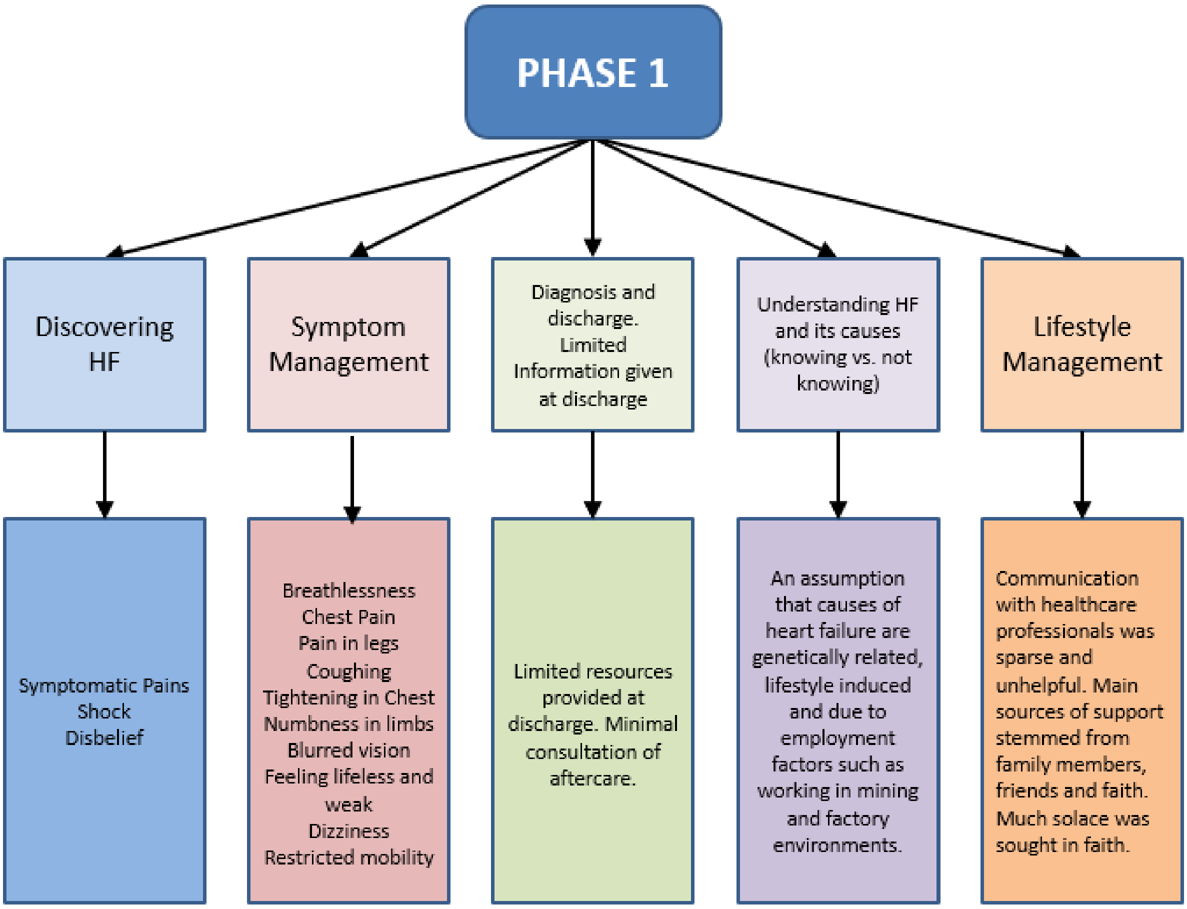
PHASE 1 / PHASE 2														
PATIENT	GENDER	DURATION OF INTERVIEW (MIN/HR)	LOCATION OF INTERVIEW	EDUCATION LEVEL	LANGUAGE SPOKEN	LEVEL OF HF (Ejaction Fraction)	AGE	MARITAL STATUS	EMPLOYMENT	WEIGHT	PREVIOUS CHD HISTORY	CO-MORBIDITIES	CARDIAC REHABILITATION ATTENDANCE	PREVIOUS CHD FAMILY HISTORY
MK	M	32/0	KITCHEN	CHS	PUNJABI	37	63	MARRIED	RETIRED	96 KG	MI	YES	NO	YES
MB	M	43/27	LOUNGE	PS	MIRPURI	35	76	MARRIED	RETIRED	63KG	MI	YES	NO	YES
NN	F	39/37	LOUNGE	CHS	ENGLISH	36	19	SINGLE	STUDENT	44KG	N/A	YES	NO	NO
MR	M	31/28	LOUNGE	HS	ENGLISH / MIRPURI	35	59	MARRIED	RETIRED	65KG	MI	YES	YES	NO
AS	F	41/37	LOUNGE	SHS	URDU	31	39	MARRIED	HOUSEWIFE	65KG	MI	YES	YES	YES
MN	M	34/29	LOUNGE	PS	ENGLISH	37	59	MARRIED	N/A	86KG	MI	YES	YES	YES
MH	M	36/29	LOUNGE	SHS	ENGLISH	36	54	MARRIED	RETIRED	89KG	MI	YES	NO	YES
FY	F	46/27	KITCHEN	SHS	ENGLISH	40	54	MARRIED	HOUSEWIFE	82KG	MI	YES	NO	NO
KM	M	37/29	LOUNGE	SHS	ENGLISH	35	58	MARRIED	EMPLOYED	97KG	ANGINA	NO	YES	NO
HN	M	42/0	LOUNGE	SHS	ENGLISH	31	61	MARRIED	EMPLOYED	99KG	ANGINA	NO	YES	YES
ZA	M	37/31	UNIVERSITY MEETING ROOM	SHS	ENGLISH	37	50	MARRIED	EMPLOYED	85KG	MI	YES	YES	NO
AS	M	27/22	UNIVERSITY MEETING ROOM	CHS	ENGLISH	39	21	SINGLE	STUDENT	75KG	NO	YES	NO	NO
GH	M	39/34	LOUNGE	CHS	ENGLISH	33	67	MARRIED	RETIRED	100KG	MI	NO	YES	YES
MB	M	41/31	KITCHEN	SHS	PUNJABI	31	77	SINGLE	RETIRED	86KG	PACE-MAKER / MI	YES	NO	NO
CB	F	35/0	LOUNGE	NS	URDU	29	68	MARRIED	HOUSEWIFE	58KG	MI	YES	YES	YES
SA	F	37/35	LOUNGE	CLG	ENGLISH	39	55	MARRIED	HOUSEWIFE	93KG	MI	YES	YES	NO
HF	M	41/49	LOUNGE	CHS	ENGLISH	31	76	SINGLE	RETIRED	96KG	MI	YES	YES	YES
NM	M	31/0	LOUNGE	PS	URDU	29	72	MARRIED	RETIRED	91KG	MI	YES	YES	NO



LANGUAGE USED	LOCATION OF INTERVIEW	LEVEL OF HF (EJACTION FRACTION)	EDUCATION LEVEL	PHASE 1	PHASE 2	PHASE 3	PHASE 4	NHS	AGE	CO-MORBIDITIES
ENGLISH	LOUNGE	29-40	PRIMARY SCHOOL (PS)	13 M	10 M	2 M	8 HCP'S	2 TRUSTS	19-79	MULTIPLE
URDU	KITCHEN		SOME HIGH SCHOOL (SHS)	5 F	4 F	7 F	2 FG	3 SITES		
PUNJABI	UNIVERSITY MEETING ROOM		NO SCHOOLING (NS)			AH - 47 MIN F ENG	1st FG - 52 MINUTES			
MIRPURI			COMPLETED HIGH SCHOOL (CHS)			AS - 36 MIN F ENG	2nd FG - 1HR 27 MINUTES			
			COLLEGE (C)			AY - 27 MIN M ENG				
						MN 32 MIN F ENG				
						GH 27 MIN F ENG				
						CB 21 MIN F ENG				
						KM 21 MIN M ENG				
						NN 31 MIN F ENG				

4.1 PHASE 1

Phase 1 identified six categories and multiple sub-categories with eighteen patients post discharge from hospital. Narrative descriptions of these have been discussed below with supporting data from interviews.



A majority of patients underwent an eventful discovery of their condition, which in turn led to a hospital admission. Patients experienced a high level of disbelief and shock when presented with symptoms related to diagnosis. The journey of discovering a heart failure diagnosis led a majority of patients to an unknown arena of uncertainty, upset and shock. It was the magnitude of symptomatic pains and the reality of treatment procedures at the point of hospital admission which exacerbated the realisation of diagnosis. Examples to illustrate such uncertainty and disbelief from heart failure patients have been shown below:

ZA: ‘It was a shock really err … I never really had any problems at all, I was very healthy, very energetic and training all the time and exercising three times a week, so when I had a chest pain and I knew it was affecting my heart. I called the ambulance and they told me you’re having a heart attack and it took them a long time to solve it, get rid of the pain. I was only 37 years old, it was you know, the magnitude of the pain was intense, it were down the left, the left arm the pain was so severe it was like the arm was going to blow out.'

Symptom management challenged heart failure patients. One of several contentions, such as reduced physical mobility, acted as a barrier to appropriate lifestyle management. Numerous tensions and complications grew from such situations that further debilitated rehabilitation. Heart failure patients consequently adjusted their lifestyle management to adapt. It was deemed appropriate to self-adjust the dosage of medicines in an attempt to reduce discomfort of symptoms. The contention between medicines and symptoms management was a reality Pakistani heart failure patients battled with. Examples of such strains have been illustrated below:

NM: 'I don't want to lie to you I drink only a little bit of water because I don't want to go upstairs to the bathroom but when I don't drink enough I feel it, my blood pressure becomes low.'

ZA: 'It's basically tightness, a lot of tightness, getting out of breath, small activities make you tired, even from walking small distances.'

Prior to discharge from hospital, patients were typically given information on how to self-manage at home. This information was provided either verbally via a heart failure nurse on the ward or through literature. The current study has illustrated that patients were not offered explanations verbally at depth prior to discharge, but rather given literature to take away to study at home. Interview data as below has discussed the experiences of information giving:

NN: 'I was given it, but I wasn't like, I wasn't like sat down and explained. I was given booklets but I'm not good with it and I don't really read, I'm not into stuff like that but I hope it gets better kind of thing.'

The need for detailed information giving was not provided, neglecting the patient's preference and ability to comprehend information. This illustrated an exacerbation of poor knowledge to self-managing at point of discharge leaving the patient with poor confidence and uncertainty about what would follow when they left hospital.

The category below demonstrated how patients made sense of their understanding as to what potentially caused their diagnosis and what heart failure was. This was blurred with much uncertainty to many patients in various forms ranging from suspecting it could be due to genetics, lifestyle factors and/or their previous employment conditions in which they worked.

NM: ‘To be honest, I don’t know what it is’ … I mean, I never heard of this before. I mean to be honest; I haven’t really thought about. I feel this was from God, this pain was God’s choice, I know humans say why has this happened to me, but this is from God.’

GH: ‘Well, to tell you the truth, at that time there was a lot of stress in my life and I smoked, it was quite heavy about 20 or 25 a day and err … the diet must have got in the way because when I came to this country, there was not oil .. everybody was using butter and the butter you know … they was using it fairly well (laughter), not just a little or something but a good half a lb. so eating so much meat and I don’t know, all these things must have you know … put the pressure on it.’

MH: ‘I think the work, because the foundry I worked there about twenty odd years, the different oils we used and graphite, it was … I have seen many people die from heart disease, my manager died, I can count more than twenty people that died. Yes, and you know it was so smoky, and once we put something in there, the furnace … the flame would touch the roof and it was very, very you know a hard place to work because when we used to work in the furnace all the smoke would get pitch black and it was full of smoke … so that’s what I think, I do wonder you know because so many of my colleagues went away with the heart attacks. I am very lucky you know, I am still living after a bypass, many of them just gone, they are dead.’

The above statements have highlighted that patients were unsure of the exact causes of their heart failure. There was a lack of clarity and confidence in knowledge. Rich descriptions of previous working conditions, dietary management, and a history of smoking were just some of the ‘guesses’ heart failure patients assumed had caused their heart failure. A definitive reality patients did acquire was the ability to describe their symptoms with clarity. Patients confidently stressed gratitude to be alive and accepted and stressed that their test from god was the cause of their heart failure which helped with the association of defining an understanding of where they placed their illness regardless of a defined scientific understanding.

The multiple sources of support played a huge role in a patient’s life; it could vary from providing a platform of confidence and assurance enabling positive management of a patient’s condition to poor communication, thus leading to a breakdown of trust and resulting in poor care. Patient experiences illustrated a high level of frustration in accessing healthcare professional support. A poor provision of information giving and access to receiving unmet needs were stressed. Poor contact with health professionals left patients unequipped with knowledge and unanswered questions. In specific, occupational support was largely failed in the facilitation of resources and equipment which would be of great benefit. Nevertheless, where patients did receive good care from family members, friends and healthcare professionals, gratitude and recognition were acknowledged.

Faith played a huge role for the respondents of this study. It acted as a comfort and support tool which gave immense strength to patients who felt that it was the foundation to the up-hill struggle of managing heart failure. The Practice Islam meant that much solace and comfort was found which in turn helped them manage their illness. A majority of heart failure patients felt that their heart failure was a test of their faith and, that it was through the gratitude and patience of their test, that they would find the ability to have a positive mental and physical outlook in addition to strength to manage.

The following statements have provided a view of both accounts:

ZA: ‘It’s just that I don’t know, erm … more access to professional or related people, you know people who are related to the hearts and all that, more access to them. I haven’t seen my cardiologist yet, I’ve seen the nurses a few times, I’ve seen the heart failure nurse twice, but a professional, as far as a professional doctor is concerned, I haven’t seen them since…’

CB: ‘Yes, we have a lot of problems with the toilet, we have no support or help with the bath and it’s very difficult to bathe. There is a little seat for the bath but it’s not stable and it collapses easily so it’s dangerous in case there is a fall or something. I just want to say that I need help with my bathing; it’s hard I suffer a lot pain getting in and out of the bath.’

MB: ‘Yes, I believe in my faith as a Muslim. Everyone believes in their faith, an Indian will believe in their faith, a white person will have a faith. I believe in Allah and if he gets upset with me my whole life will fall apart, I keep him happy and look after my health and I feel better, my religion supports me. My Allah asks me to not forget him, I pray and ask what I need from him, Allah gives me what I need I pray everywhere I can, I ask for health, I ask for the ability to walk and keep talking I do not want to be a burden on anyone ever, I don’t want to become reliant on anyone and not be able to not manage myself, do you understand? I have to keep active; being a burden on anyone is a bad thing, if I ask for anything from children it’s not nice, but if I don’t have health I have to. I have to meet Allah half way, he supports me, but I help myself too by prayer for anything I need. Allah helps and supports everyone if you remember him.’

Lifestyle management was a key factor in the maintenance of positive health and key to cardiac rehabilitation. This category explored how patients looked after their health post discharge including accessing on-line resources, outlook, managing risk factors including management of medication, diet, exercise and co-morbidities. Insights into the types of coping mechanisms have been cited below:

MB: ‘The thing is, I take my medicines and walk... with my food I used to eat two chapatti and now I eat one chapatti, I can’t eat more than one, I don’t feel like it, if my heart is happy with eating fruit I will eat it … I go to my doctors and meet with the nurses and they take blood tests when they need to. In the evenings I eat chicken and meat and I eat vegetables too.’

HF: ‘It’s miserable, it’s really miserable for me now. I wish I could die you know, if I was in Pakistan I would have gone by now, but the doctors here they … they really care about you … I cannot, you know hoover because it affects my pace-maker, I can’t go shopping centres, they have camera and that could affect my machine, I can’t do a lot.’

Managing the emotional self was described as a very challenging struggle. It was physical, emotional and mental. Patients felt miserable, upset and very depressed as they were no longer able to carry out the tasks they used to. The disability, lack of mobility and the divorce from the heart failure patient’s former self of being able to enjoy life was a genuine debilitation. Living life was remote and often felt isolated. However, an understanding of living in the UK where the National Health Service (NHS) facilities were amenable meant patients appreciated immensely the gift of life and treatment they received, as the alternative of living in a country such as Pakistan would leave them with a poor quality of life if not a premature death. This appreciation was stressed continuously and throughout by patients. In addition to the diagnosis of heart failure, co-morbidities played a huge role in management of illness. Diabetes, whether controlled by insulin injections or tablets, meant that patients had additional management of medicines and symptoms making coping with heart failure difficult. Further co-morbidities such as cancer diagnosis and treatments, thalassemia, constipation, asthma and arthritis worried and disabled patients to have positive management experiences of heart failure alone as such co-morbidities and their symptoms added to the pressures and demands of management of illness. Examples of such have been illustrated below:

SA: ‘It makes me depress. It has affected me so much, sorry if I fall in tears (patient starts to cry). I can’t do my normal activities; I can’t go to the shopping, unless they take me into the wheelchair. It’s so much, it’s like 75% I am gone. I want to do things, but I can’t do.’

(heart failure patient begins to cry and a break is taken)

‘I can’t go shopping, my friend’s house or in the garden, those kinds of things I miss a lot… I can’t travel. It’s not like before, I haven’t been to my friends for six months now, it’s just at the front of my house. I feel alone, I stay cooped up in my room alone, and I am by myself. I don't know what's going to happen, it does affect you.'

MN: 'I don't know what to do because my heart is weak plus diabetes. I used to be on tablets but now my doctor, he's an Indian doctor and he said you need injection. I have one injection in the morning and err … sometimes; I take three injections because of diabetes. I have bad feet and my legs spasm and the doctors and nurse said it's not because of the heart but because you also suffer from the diabetes. I am weak in sex life, I have to masturbate so, and I don't know what's wrong with me.'

NN: 'It was the numbness, I thought I was going to collapse, and I felt really bad, I had blurry vision. It was my sugars and it was 25, that's high. I would go for my blood transfusion I would say to them I'm feeling tired in myself and blood pressure was really low, but they thought that was normal, like when I got admitted before, my blood pressure was really low and when I go the hospital back every month for my transfusion they say that's like normal for you, but I knew I wasn't feeling right, like my knees were hurting and I do get pain in my body because of the thalassaemia, I do get pains in my bones and that but this pain was different. I try my best but I have my ups and downs, like with my insulin, I don't want to keep giving myself injections, it's a hassle to get the food right and count carbs.'

Dietary management was varied amongst patients, whilst some patients made a conscious decision to be healthier and reduce their portion sizes and incorporate healthier foods and substitute, other patients refused to make changes as it was very difficult for them to disregard 'our foods' mainly curries and chapatti. Such cultural values were important for many heart failure patients as it satisfied dietary needs in addition to addressing comforts which had very much been an integral part of their community and traditions. However, on the other hand there were patients who due to the severity of their illnesses had significantly reduced appetites. Weight management and salt in-take were monitored by a majority of patients and adhered to but namely in hospital settings and not at home. Examples of these have been illustrated below:

NM: 'Everything is normal, diet, exercise … I should eat more greens, healthy foods that's what they say, but Asians can't survive on that to tell you the truth we need the chapatti and curries and rice and things like that, I can't survive on English foods because I'm not used to it. I eat a little; I try to keep my weight down. I don't want to increase my weight, believe me I eat nothing all day just in the evening I eat two chapattis with curry, I don't eat fruit, I don't like it nor milk and no other junk foods just only my two chapatti's with curry whether it's with vegetables or something that's important to me, I have to eat that.'

AS: ‘I used to weigh a lot and but now I have lost weight, I have halved my food portions now.’

HF: ‘No, it’s … chapatti and curry, that’s our food and what I eat, no changes. Sometimes I cook rice, but majority of time chapatti and curry. I eat a lot of meat which I should not, but I do. I take a lot of salt and weigh myself only when I go to the hospital.’

ZA: ‘There has been a change; I’ve stopped eating all buttery things. My wife and my mum would cook all the curries in ghee, but now we use olive oil and only a small amount as well. The fried stuff has really been cut down, the kebabs and samosas, I was never really a fan of them before anyway … sweet stuff, you know foods like gajrala (carrot sweet) and ras malai (milk sweet). I just have them on a special occasion now anyway.’

Physical activity was an essential part of recovery and maintenance of health. Whilst patients acknowledged the benefits of exercise, barriers acted as deterrents causing exercise to be a challenge. Physical barriers prevented patients from exercising as their symptoms dictated inability and restriction. Patients were restricted physically as it would exacerbate their symptoms. Other barriers included poor weather conditions, employment priorities, co-morbidities, poor access to transport, and the travel expenses of attending a gym or cardiac rehabilitation classes despite knowing it would be a supported and uplifting environment they would gain from and enjoy.

FY: ‘Exercise, no because it’s cold weather, can’t do it … sometimes I can walk and sometimes I err … sometimes I do sit-ups, yes that’s light, I can’t do heavy lifting because my breathing is heavy. I haven’t got the bus pass and I can’t afford, there is no money. This is problem, I like the gym and I go and I enjoy myself, my weight is go down and I feel very well and err … my body is heavy and my everything is err … feel not better. I go exercise and I take and feel better, but I can’t’ afford this to go by bus, by taxi I can’t afford it coming and going back. I ask this hospital, I say I come proper but I can’t afford everyday … sometime I go, sometime I weekly go, three to two times I go other time I can’t go … she said come in regular but I can’t. The bus fare is expensive, everything is expensive.’

AS: ‘They have given me exercises and told me to do but I can’t go out from the home, I don’t leave the house. I pray five times a day so I exercise with my praying and keeping busy with the children and getting them ready for school and working at home and in the shop, I keep myself busy and that is a form of exercise. I know there is a special type of exercise, exercising properly but I don’t do that.’

ZA: ‘Erm … it’s a good thing, cause it gives out a security kind of thing innit, you know if something does goes wrong you’re in the right place, and when I’m out there with my condition and I’m reluctant to do this or that I question is that going to be too much for my condition, am I going to harm rather than make myself better but here it’s programmed and people are watching over you here and if something does go wrong then you’re at the hospital so that gives it more confidence to come and do more exercise. I normally come twice a week and I think cause they assess you and they know your medical condition they set the programme accordingly I think that’s quite beneficial to people.’

A repetitive trait of a majority of patients was that of immense gratitude of being able to be in a country such as the UK where healthcare catered for medicinal needs and were free on the NHS. Nevertheless, concerns of taking multiple medications and additional medicines such as insulin, attending blood transfusion appointments and managing side-effects proved to be a very stressful anxiety. Aids such as dossettes helped with management of medicines despite not having a full understanding of the exact purposes the medicines served. Patients felt that, as a result of taking their medicines, symptoms were managed allowing physical mobility and alleviation of symptoms. Unfortunately, this at times meant that heart failure patients adjusted their medicines to smaller doses in order to avoid climbing stairs to use bathroom facilities. Examples of such concerns and methods of medicine adherence have been illustrated below:

MK: ‘I am telling you, I take two water tablet in the morning and two in the evening, if I don’t take them then water goes in the lungs and breathing becomes difficult and that’s when the trouble starts. That, I would say that when I take the tablets I am cured, that’s when I am okay but right now I am depending on the medicines and the water tablets, but basically water is very important.’

MK: ‘I mean it’s thanks to god that I am here in this country, you can get medicines, pure medicines plus they give it free so err … if I was in Pakistan abroad this is impossible. You don’t feel safe to go to Pakistan; you want to go but if anything happens over there then the doctors can’t help.’

GH: ‘I’ve been taking them for the last 25 years so I’ve been asking them and sometimes I ask the doctor or the pharmacists or I look myself in the computer, sometimes what it is for and you know I have found out about it and I know. I’m taking too much tablets, I mean I’m taking about 17, 18, 19 tablets a day … which is continued for last 25 years you know and because of that, you know I don’t feel very well now, before it wouldn’t have bothered me but now I feel nausea sometimes and you know and sometimes the dizziness … you know different kinds of thing, I think it must be this chemical effects now, that it is affecting me that way, this is the only concern (laughter).’

ZA: **‘**Erm … the slight concern is that what are the long term effects that it will have on my health innit, you know like the kidney failure, liver function to mention some innit and things like that, it’s like jumping out of the frying pan into the fire innit, that worries you, you fight one illness and you’re getting into another one. You might develop another illness from taking another all the medicines innit. That’s my main concern at the moment but at the same time I do understand that I have to take these to cope with my current situation. I remember to take them myself in two sessions in the morning and evening. I put them in the cupboard, this is the morning one and this is the evening one and that’s it and takes them around about the same time. Yes … it’s computerised now (laughter), I’ve been taking them so long now.’

4.2 SUMMARY OF PHASE 1 FINDINGS

Phase 1 highlighted heart failure patients reflecting a growing awareness of multiple symptoms which was eventually recognised as a health problem. The importance of the perceived health threat to the heart failure patient appeared to be reflected in the degree of detail with which they described the pain. This recognition of symptomatic pain was significant to heart failure patients, regardless of varying symptoms. Discovery of diagnosis came at a time of distress, confusion and shock to many patients. Upon discharge, patients described a poor output of detailed explanations on how to self-manage appropriately. A pamphlet given at the time of discharge led to both arbitrary and limited knowledge of what exactly heart failure was, its causes and how to self-manage the condition and related co-morbidities.

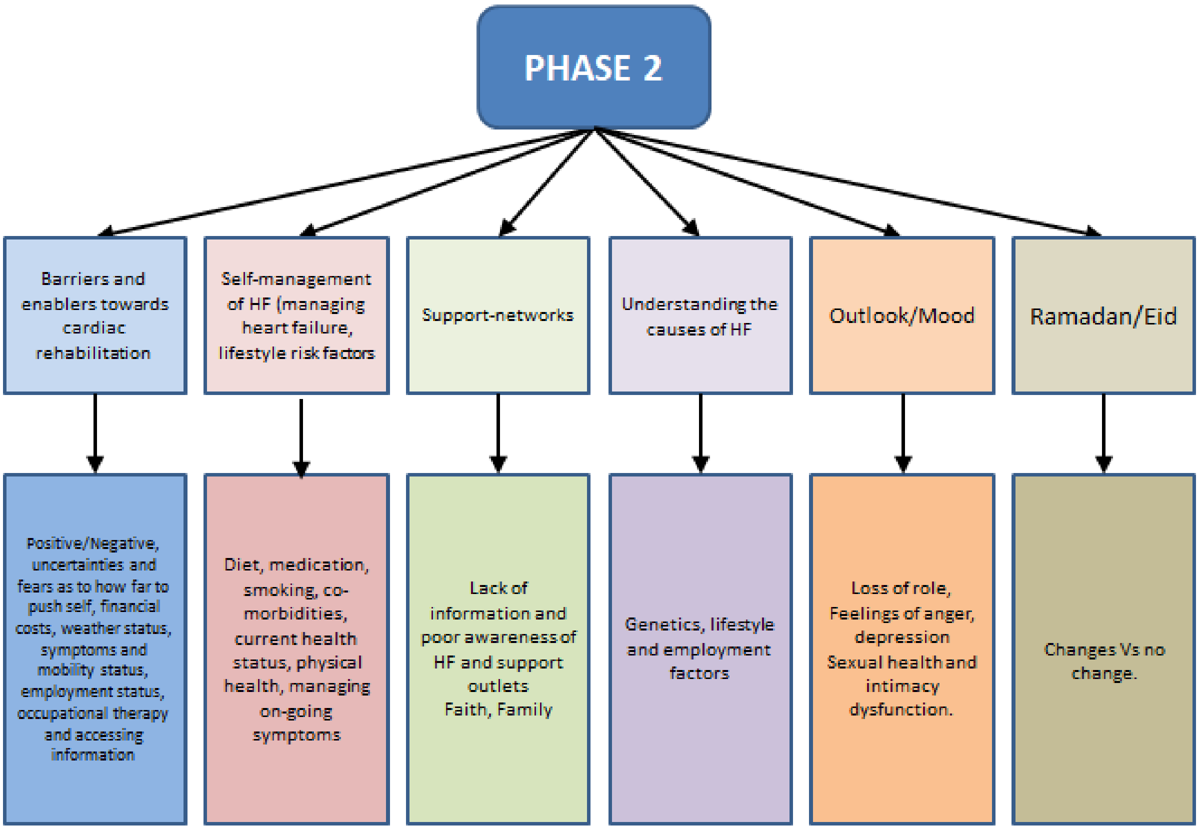
Consequently, this left patients feeling confused and frustrated as they were unable to fully comprehend the nature of their condition and thus self-manage efficiently. A majority of patients when asked what heart failure was and what they felt caused their heart failure diagnoses were unable to respond with appropriate answers. Illustrations of understanding were poor in descriptions of no understanding, to having never heard of the term heart failure came across from heart failure patients. Patients described heart failure better in the form of their symptoms they experienced rather than what they had been advised medically. Patients described causes being related to God’s will (fatalistic), smoking, poor diet, lifestyle choices, employment conditions they had previously worked in, co-morbidities, lack of physical activity, weather conditions and personal stresses in life.

Lifestyle management included medication adherence, dietary management, physical activity and management of symptoms. Managing physical activity was incorporated for many women as part of their daily home chores as they prioritised homely chores above themselves and their well-being outside the home. Barriers at the forefront of preventing patients from exercise included poor weather conditions, travel costs to attend cardiac rehabilitation, lack of energy due to symptoms, and co-morbidities. Patients understood the importance of staying healthy and the benefits of exercise especially as these also provided a social outlet at cardiac rehabilitation centres. When asked about attending cardiac rehabilitation patients also stressed the travel expenditures which made it difficult to attend. Concerns were also raised by patients who stressed that health professionals failed to invite patients to attend cardiac rehabilitation. Patients were not clear on the reasons they were taking their medicines, though there was immense gratitude and a blind culture of taking medicines. Understanding its causes, purpose and need was not comprehended leaving patients blindly adhering to medication and having numerous unanswered questions relating to side effects. A minority of patients reported a poor adherence to medicines as it was disliked simply due to the sheer quantity relating to heart condition and addition co-morbidities. Managing diet and weight post discharge was positive in the short term. However, poor behaviours soon reverted back to attitudes of eating what one liked, thus making no long-term changes. Portion control, substituting and avoiding certain unhealthy foods were again something that lasted only for a short period of time.

Co-morbidities exacerbated symptoms for a majority of patients making it very difficult to manage heart failure efficiently. This led to a poor quality of life. Patients described the inability to enjoy foods, exercise, and part-take in intimate relationships with partners. Patients felt insecure as they had so many unanswered questions that they wished to discuss with health professionals regarding prognosis, self-management and related co-morbidities. Subsequently, a majority of internalised assumptions of self-managing took place which led to the hypothesis of causes, reasoning with self as to what boundaries and restrictions were appropriate with management and unsupervised ad-hoc arbitrary controlled health schedules. A general shared consensus among patients was that of a feeling of being left unsupported by healthcare professionals who did not comprehend their concerns, fears and anxieties. Sources of support brought together mechanisms to cope better; these were mainly external to health professionals that included faith as a great mental solace, family and medicine’s adherence.

4.3 PHASE 2

Phase 2 identified five categories and multiple sub-categories with 14 patients. A 12-week period took place prior to re-interviewing heart failure patients post discharge from hospital. A description of these has been discussed below.



Phase 2 of the study began 12 weeks post discharge from hospital. It was a time lapse of 12 weeks when patients had had some time to absorb the nature of their syndrome and manage their on-going illness on a daily basis, thus exploring the progress and the experiences of these. It was also a time when their family caregivers were immersed in their roles. Interviews with family caregivers were carried out post interviews with patients at phase 2; these have been discussed in phase 3 of the study.

A majority of the patients faced many challenges in coping with heart failure. These barriers were looked at more closely in order to understand the types of difficulties endured in managing heart failure. Patients faced many challenges in their recovery. Symptomatic pains and physical barriers continued to act as a preventative measure in being able to be mobile and active. Furthermore, financial strains and stressful employment commitments restricted patients in being able to attend cardiac rehabilitation. Patients felt deflated within themselves due to the inability of being able to carry out tasks such as self-caring, thus leaving them dependent upon family and friends. Subsequently, this resulted in patients stressing the need for emotional support, an outlet they did not have. Below, examples have been given to illustrate heart failure patient progress post a time lapse of 12 weeks since discharge from hospital:

FY: 'Err … I think so, I start the gym but it is the catch bus and I can't afford it, it is too much … you know the bus fare is too expensive. I can't … you know if someone is disabled and they have pain and they have the free bus pass, some people is original sick and they no give free bus pass, this is difference. I like gym, it is good for health but I can't afford the bus, every day you spend £5.00. I can't spend it.'

SA: 'Yes, I have. I have made progress. I am feeling a bit better. I am just depressed when I am sitting at home. I used to go out, you know window shopping and I used to do voluntary work. I can't go out so I am feeling more depressed, for a year now I don't go out. I talk to my daughter … she just calls the doctor. I don't want that, I just want to talk to someone who will listen and understand but she doesn't … I am missing, emotional support, I just want to talk to someone who will understand but she will just call the doctor and I really get angry with that.'

The causes of heart failure as perceived by heart failure patients did not differ from the first phase of the study in that heart failure patients continued to feel unsure and uncertain. The causes were assumed to be due to lifestyle management, age, advanced co-morbidities, genetic factors and Allah's will, a repetition from the first phase of the study. Ramadan was adhered to by only a minority of patients. It was not a requirement for patients to adhere to fasting as they were all medically exempt. However, those who chose to fast during the month of Ramadan adjusted their medication and diet accordingly, without medical supervision. A similar line of thought was also adopted at Eid and other celebratory events where patients adjusted their diets to a controlled regime. However, a minority of patients expressed the complete opposite whereby they continued to eat as they wished at times of celebratory occasions applying no restriction, below examples of such lines of thought highlight these points:

NH: 'It is certainly our lifestyle, the thing is particularly our food you know this thing is we are careless about, we are Asians and the Asian food is salt, sugar and oil, those three things are used in a lot of quantity so probably that is the cause of cholesterol and blood clotting and you know blockage of the arteries but at the same time thanks god I have never smoked in my life, I have never drink in my life so these are the two things that worsen the condition so this is how I can see the awareness in the Asian community is very important about the foods and lifestyle, yes.'

GH: ‘Oh, I eat anything (laughter). I eat anything except the … if its gajjar halva (sweet carrot dish) because I eat less if I can because it’s got a lot more grease.’

ZA: ‘I will give it a go to start off with and see how things plan because I’ve got diabetes now as well so last year I did fast and I managed all right so this year because I have had this procedure now, it’s something different. I will give it a go sort of anyway.’

A majority of patients perceived an altered relationship with their outlook and mood in that they experienced multiple mood swings, became angry quickly and experienced feelings of depression and low mood. A loss of role to the former self meant that patients felt detached and isolated. The psychological impact of heart failure meant that patients became quite anxious, fearful and defeated at times during their illness recovery. Examples of these have been drawn below:

MB: ‘I feel worried; I am always anxious and worried all the time. My health is okay, but I do think about it. I can’t go out much anywhere because of the pain I am in, it’s hard but what can I do?’

MH: ‘I get angry quickly … fighting a lot with family because I am fed up with my problems innit but sometimes I sleep a lot and then when I wake up I am shaky and I can’t walk, it’s difficult. I know the heart is too weak and I have a kidney problem and after one week I have the dialysis as well. I had some sort of a depression condition but now sometime I think it’s due to the weather change you know also most probably but now my heart condition has improved, my blood circulation is well. I have err … suffered for four or five years you know with erection dysfunction and that is for the last three weeks or so now, that problem is solving. I used to seek medication to help for it but now I don’t need it because I am better so yes, yes this is how I feel now.’

Sources of support ranged from health professionals, family and friend members to medicines and faith. However, patients did raise concerns where they had not received the care they deemed important and expected. For example, informed consultations and support for patients which would help manage their heart failure diagnosis both financially and with personal healthcare needs were sources of support patients very much additionally craved. It was collectively agreed that health professional support was very little in the way of explanatory guidance and information giving. Much disappointment in the way of service provision was highlighted; lack of information left patients in the dark about their long-term recovery and prognosis. This was similar to phase 1 of the study in that patients were discharged with minimal information giving, leaving much confusion and uncertainty with how to manage heart failure as demonstrated below:

GH: ‘I mean it would make me feel better and the other thing is I would explain my problem to him from time to time but now if I have problem I have to wait six or seven months before I go and see him, I think that’s a long time. I hear from my doctor that he’s a very good consultant but I don’t know, I got a feeling that he’s you know that he’s a very careless person, he doesn’t care much …the care is not as it used to be.’

ZA: ‘I was working and I was self-employed and err … I couldn’t work straight away and I had no money coming in and there was nobody to advise you about what benefits you could claim and this and that. They should have told me what benefits you could claim but Alhamdulillah I did well, I got back and started a different type of business and physically I am not physically involved so I’m managing okay now.’

KM: ‘My wife innit, she’s only there for me and the kids too, the boys. If they see me they will say go to bed and have a rest. They support me very well.’

There was a consensus amongst patients that exercise was a beneficial activity. However, though in agreement of this, it was not necessarily an activity in which every patient could engage. Physical barriers deterred patients from being able to exercise which in most cases meant that either patients could not exercise or that they were limited to short walks within their homes or locally within the vicinity of their homes. External barriers to physical health included poor weather conditions and lack of travel expenses which prevented patients from being able to attend cardiac rehabilitation exercise classes. Unfortunately, there were instances where family members prevented patients from attending as they were over-protective of the patients’ health and worried that exercise may exert the patients resulting in a decline in health. Furthermore, instances of patients not being invited by healthcare professionals also occurred, this clashed with the patients’ desires to attend. Patients who did engage regularly in exercise found it extremely enjoyable and beneficial. It was an activity that was socially engaging in addition to improving physical and mental health. Cardiac rehabilitation classes provided tailored programmes to patients attending which helped with physical barriers in addition to confidence in a supported and secure environment with a team of healthcare professionals. It was a beneficial challenge which aided in the promotion of heart failure management as illustrated by the following examples:

AS: ‘There has been a big difference in comparison to before … before I was very weak and I felt dizzy, like I was going to fall but not now. I do feel that I have improved day by day. Before I couldn’t do much but now I can do a lot of things but now I can, so that’ all good.’

MB: ‘No. I am not going to stop smoking. There is no point in thinking about watching anything, I am just preparing for my grave to meet my lord now, and it’s that time now … that time has come now. I will die one day, what is the point in watching everything I eat, I will die regardless. I went for a walk yesterday but on my way back I held on to walls and with great struggle made in into my garden and came back home. I was feeling very dizzy, my sugar was very low and that's what make is hard to. I have no energy at all, I feel weak.'

NH: 'It's a mixed class, both men and women. It is a small charity so a few people are there and sometimes ten people or twelve people and then they give very personal attention to each person you know …they are well trained people and they have tailored programmes for people with heart problems so it is good in my opinion.'

SA: 'I haven't been able to do any exercises at all. I haven't been able to anything, I want to do but I can't do. I was telling my daughter to take me to gym but she won't take me because she is scared. I can go to the gym and go to the rowing machine and sit on the bicycle but she doesn't take me.'

Medication management improved from phase 1 in many ways for patients; a better understanding of the purpose of taking medication became clearer in addition to adherence despite a dislike for the multiple medicines administered and their side-effects. A strong sense of gratitude continued as patients felt that the medicines helped keep their health in control and prolonged their lives. A majority of patients made successful changes to their diets and weight management. For example, patients reduced portion sizes and eliminated many unhealthy foods through substituting food choices and/or changing methods by which they prepared their meals. However, some struggled in the adaptation to healthier foods, continuing with diets that were unchangeable and staple to patients. Below, illustrations of viewpoints put across have been presented:

AS: 'I take my medicines, I used to take my medicines but I didn't know what they were for, but now I have an understanding. They have told me, they told me at the hospital and they wrote it for me, what I should eat and when. I used to feel very tired and lack energy but now I am able to do all my housework. I never forget, I always remember to take them.'

NN: 'I have also got my insulin and my heart tablets and my tablets for thalassemia as well so it's quite a lot in the day so I'm like … I won't take it. It's just that I look at them and there are a lot of them. I don't like taking the tablets. I can't really be bothered to take them. If I know what it's for and what it's doing, I'd take them. I don't even know their names.'

FH: 'I can only cook curry and chapatti, that's all and sometimes vegetables, its Pakistani food.'

GH: (Coughing and laughter) … 'I don't eat few certain things, like grease shall we say. I mean butter, I haven't had it for years and years now, and err … sugar intake is very, very little, mostly I use sweetener in tea and err … as far as the meat is concerned I love it so I eat it but err … then it's limited to two or three times a week, I have big portions.'

MB: 'I used to eat two my chapattis but now I can only manage one and a half or maybe one chapatti. I have lost my appetite; I just don't feel like eating much. I have gone to hospital, they have weighed me and I have lost a lot of weight.'

MB: 'No, I can't change or restrict anything … I eat whatever I like, whether I eat or little or a lot I can't stop eating what I want to (laughter). I can't restrict myself from any foods, I have diabetes but I can't stop eating what I want, I just had three spoons of sugar (laughter).'

NH: 'Yes, of course the food has been changed … we are doing our best to follow the dieticians you know, their advice. I am sitting at my night job and I have my lap-top there so I go on to the internet and it is good because it helps, thanks god I have a good habit of reading newspaper and the health pages on the local daily paper I read… wherever I can find a piece of information it is good for me.'

4.4 SUMMARY OF PHASE 2 FINDINGS

Post a 12-week period of discharge from hospital, patients immersed themselves within the culture of their home environments as they were accustomed to prior to admission. Challenges arose however when the reality of self-management brought about on-going struggles and uncertainty leading to confusion and unstructured management. Patients described their mobility as poor due to the lack of occupational support and symptomatic difficulties. Fears and uncertainties of a recurrence were at the height of patients' worries. Financial strains of unemployment prompted concerns as being able to provide for the family was challenging. Patients felt worried that their families would suffer because of their inability to earn and provide financial stability. Patients also stressed that they were not made aware of support agencies that would provide them the knowledge of benefits that would help in the interim of recovery.

Transport costs to attend cardiac rehabilitation were of concern to some patients. The inability to cover financial costs for transportation acted as a barrier when attempting to make an effort to attend and progress with physical recovery. Similarly, weather conditions made it difficult for some patients to engage in physical activity. For example, if the weather was cold, it was deemed inappropriate to go out; therefore, patients opted to stay at home. Patients struggled to understand the causes of their diagnosis and were quite arbitrary about the responses they gave. These ranged from genetic causes, lifestyle choices and/or working in poor employment environments. Managing diet, medication, additional co-morbidities and subsequent symptoms, and if applicable smoking, were an overwhelming struggle for most patients; these have been described in their segments.

A majority of patients wanted to adhere to an active lifestyle and of those that attended cardiac rehabilitation within a gym setting at a hospital site, the feeling of contentment and security was expressed leading to confidence and empowerment of their condition.

Patients reported of the support networks around them. Family, partners and in particular faith provided heart failure patients with a positive outlook. Patients reported they were feeling much better 12 weeks post discharge and were coping better with symptoms as medicines were helping them manage and control their pains and ailments. However, a minority of patients reported feeling worse and felt their health was deteriorating, physically and emotionally. Patients described co-morbidities restricting mobility, feeling tired due to multiple symptoms and pains and suffering from internalised fears of leaving the home in case a recurrence of an emergency arose.

Eating healthier, reducing salt intake, reducing portion sizes and substituting for healthier choices were a lifestyle choice that was adopted. Reducing the intake of oils, sugars, and fried foods was adopted and substitutions such as more fruit, vegetables, salads, white meats and fish were incorporated.

Nevertheless, there were aspects of managing diet that remained a struggle. A majority of patients refused to give up ‘their own’ foods which hindered changes in adopting healthier strategies. Eating foods of cultural and ethnic value was an integral part of the heart failure patient’s ethnicity and palette. Diet was considered to be the foundation of a culture from which heart failure patients flourished their appetite and remained to have some control over; it was enjoyed by heart failure patients and it was a pleasure many heart failure patients looked forward to daily. Thus, the importance of ‘our foods’ was considered an important priority in managing the aspect of dietary intake. Furthermore, dietary management for a minority of patients was a difficult task in that feelings of eating times evoked a time of panic and worry as those with multiple co-morbidities struggled with eating foods that would impinge on controlling their diabetes for instance. Accurate measures of carbohydrate counting in order to align and match levels of insulin were an important factor.

Heart failure patients reported the diagnosis of heart failure to be a downward spiral of loss of control and enjoyment of life and a somewhat emptiness in the quality of life heart failure patients could lead; and so, the control and enjoyment of eating what one wished was a joy that could not be lost or taken away. Taking the advice of personal trainers and taking guidance in dietary advice to keep control of both weight management and food intake were imperative to moving forward with better management of this particular lifestyle risk factor.

Medication management had slightly improved in that patients had more insight, awareness and understanding of what medicines they were taking and why. Patients reported their symptoms improving with improved health, the measure of this came from the volume of medicines decreasing in some cases. Patients adhered to medicines via a fixed routine which was fixed throughout set times of the day using blister packs and family caregivers' support. Much gratitude was expressed to health professionals for providing medicines that improved and controlled symptoms which prevented readmissions and reoccurrences to hospital. However, despite the positive attributes, patients reported many difficulties they had with medicines adherence. Side-effects such as nightmares, dizziness, dryness in mouth, constipation, tiredness, feeling of weakness and muscular pains and aches were amongst the symptoms that patients experienced. These left patients feeling, in some instances, more deflated as side-effects were causing additional difficulties in outlook of their general health and mobility.

More conscious of health now post a 12-week period, efforts to be healthier, take public transport, walk more and eat healthily, keep active, and manage medicines were a part of an effort to improve health. Attendance to cardiac rehabilitation was a priority. It was reported that physical activity was carried out within the home setting or locally to the shops as the costs of affording gym membership or travel to the hospital gym were limited. However, restricting barriers to physical mobility were due to pains in body, feeling dizzy, breathlessness, feeling weak and aches and weather, in addition to the lack of awareness of cardiac rehabilitation. Those who attended cardiac rehabilitation classes reported that there was improvement in health, confidence and reassurance that exercise was safe and enjoyable. Patients also reported that family caregivers held back family patients from attending cardiac rehabilitation due to the fear of symptoms and health reclining.

During the sacred month of Ramadan, it was permissible for patients to abstain from fasting if they were unable to do so due to poor health. Whilst a majority of patients did not fast due to their heart failure and related co-morbidities, a minority of patients who felt they could cope with fasting did so. They adjusted their eating schedules and took medicines to align with times of fasting (sunrise to sunset). It must be noted here that this adjustment took place without any medical intervention from health professionals. Physical activity was put on hold during this month with a view to not over-exerting the body prompting any symptomatic and physical distress. Patients felt strongly about fasting as it was reported that it helped them mentally and spiritually to cleanse themselves despite a reshuffle in schedule of lifestyle management. During times of celebrations, a majority of patients said that they continued to eat as they wished and did not withhold from foods they enjoyed. A minority of patients applied restrictions to their lifestyles at all times and so such celebratory times did not affect their daily lifestyle management.

Patients described their mood and outlook to have changed considerably post discharge as it became apparent that they became angrier and lower in mood as time lapsed. A deflated and depressed mind-set crept in making it very difficult to feel emotionally positive. Being short-tempered and angry was a recurrent category that was reported by patients. Feelings of hopelessness and feeling a 'loss of role' were very much prominent. A description of a poor social life involving friends, partaking in charity events and community projects and lack of employment were reported. Furthermore, carrying out daily chores and tasks became difficult and challenging leading to feeling remote and isolated as the recovery period progressed and adapted.

Support networks included partners and children, immediate family and Allah. Faith played a major role in patients' lives; it was a source of solace, comfort and strength. Family took it upon themselves to share responsibilities and split tasks to care for patients. A major concern of patients was that they felt unsupported by health professionals as they wished to be more supported and informed of their health status and resource needs. Nevertheless, a minority of heart failure patients relied solely on health professionals as they did not want to burden or worry family members. Patients described a lack of emotional support that was not understood by family and so therefore felt lonely and had no outlet for their feelings. The impact of heart failure and related co-morbidities left patients feeling empty and unresolved, fears of recurrences were a worry as were not being able to do activities and be as mobile as they once used to be. It was stressed by heart failure patients that they felt they were not being taken seriously by health professionals, ignored when requiring appropriate occupational health care support and given appointments that were short in their consultations leading to patients feeling uneasy to ask questions regarding their health concerns.

Understanding the causes of heart failure was sparse and ranged from a belief that it was Allah's will, a weakened heart from having multiple heart attacks, poor diet, smoking, not known, as a result of co-morbidities and possibly being linked to a genetic predisposition and poor employment exposures. This was neither confirmed nor explained post discharge or further along in the heart failure patients' journey.

Smoking was an on-going activity for a small minority of patients; whilst a majority of patients had stopped smoking, the acknowledgment of once having smoked up to and beyond 60-80 cigarettes daily was a contributory cause of heart failure. Those who continued to smoke felt justified as they would die regardless.

Data findings revealed several gaps within phases 1 and 2 of the study, which would be of benefit to addressing the needs of Pakistani heart failure patients.

A majority of patients felt strongly about eating any other foods outside ‘their own’ staple diet. Patients were reluctant to adapt to changes as eating what they knew best in an environment that was comfortable to them. Patients very seldom weighed themselves outside hospital grounds resulting in poor monitoring of weight management. Through the holy month of Ramadan, a minority of patients adjusted their medicines and diet without informed knowledge. In contrast, a majority of patients were unable to fast, this was religiously permissible. Heart failure patients stressed that healthcare professionals failed to inform patients of exercises they could do safely within their home settings.

Patients had complete faith in medication and showed immense gratitude for their medication. However, there was a concern with the lack of knowledge concerning side-effects and understanding of the purpose their medicines served. Further knowledge and purpose of medication would benefit patient adherence and understanding. It was stressed by heart failure patients that a detailed explanation would aid the understanding of the management of medicine. Patients had multiple co-morbidities making it challenging to cope with heart failure. Symptomatic management brought many challenges to mobility in addition to medication management.

Faith, family, friends and on-line resources offered support and solace in helping heart failure patients manage their knowledge as it helped educate them about their condition. Faith was deemed to be a pivotal aspect of support; it acted as a positive mechanism to which heart failure patients upheld their health three-fold: physical, spiritual and mental. It was the foundation on which heart failure patients built their strength and courage upon keeping them motivated in all aspects of daily living.

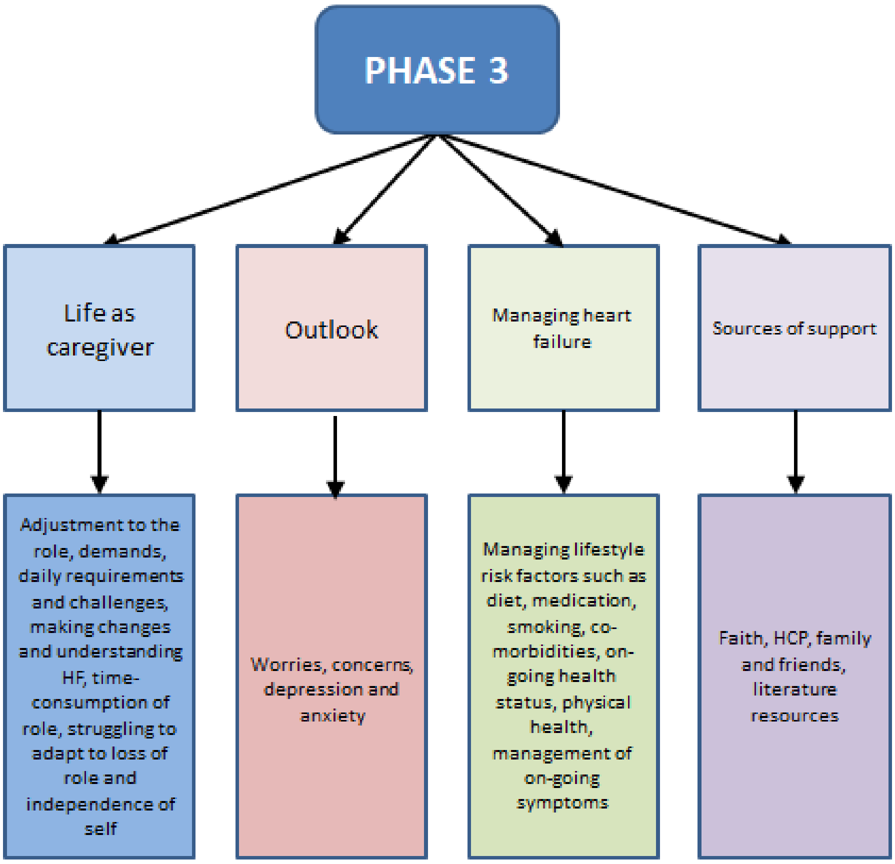
Knowledge of what heart failure was and how to self-manage effectively accounted for specific needs as stressed throughout this study were essential. In addition to the standard cardiac rehabilitation needs and related occupational needs, the underlying thread that wove together patient care were an understanding of cultural, religious and ethnic strands that were the essence of the foundations upon which Pakistani heart failure patients built their lives. Cultural sensitivity and awareness of information delivery accounting for values that were important to patients was essential in moving forward and building efficacy of service provision.

5 CHAPTER FIVE: FINDINGS – PHASE 3

Phase three of the study provides insight into the family caregivers’ experiences of living with heart failure.

5.1 PHASE 3

Phase 3 identified four categories and multiple sub-categories with nine family caregivers. A description of these has been discussed.



Adjusting to the role of a family caregiver proved to be demanding and challenging in numerous ways. Living as a family caregiver involved being hands on, family caregivers ensured they prioritised the patient’s needs and demands first whilst neglecting other duties and family members. For a majority of the time, it was a straining and challenging role which left the family caregiver feeling very tired physically, and emotionally frustrated. Below examples of such experiences have been given:

IB (daughter-in-law): ‘It’s like 24 hour care really, I mean you can’t go out as much as you used to and I mean I used to go to the gym but I can’t go and do that anymore … spending time with the kids has been cut down because sometimes in the night you have to get up and run around after her, loads of things have been changed, but you have to cope with the. I think because she is very stubborn lady, she is stubborn because she wants things her way and you have to work around it somehow … you just have to see how it goes. I am stuck here with her at home.'

MN (daughter): 'Initially, for the first few months it was really intense … it was everyone was taking time off work and you know just, trying to be here as much as possible whether that meant taking shifts or communicating more with each other to take him to appointments or making sure medication was okay and making sure mum was okay because the older they get they can't handle this responsibility and looking after guests so the whole situation we had to really be on guard and just work our way through it and now I've realised it's much better, you know it's much calmer and now it's making sure that we've got the right amount of food and so we get home and cook and make sure he's not rubbish foods and taking his medication. It's not as intense but at the back of your mind you have to anticipate appointments, medication and make sure his medication is not running out and to check he's not having any problems and start getting out because he won't mention it unless he's in severe pain so you have to anticipate it all. You become more thoughtful of the situation I think because of what's happened.'

NN (mother): 'It's affected a lot … she had thalassemia and diabetes but with the heart failure I just don't know what is going to happen to her now, it has affected me a lot. Every night I just can't sleep because I am thinking what's going to happen (crying). It's affected me a lot as a mum, like my other children … I care for my daughter more than them; I am always leaving them out and thinking about her but I can't help it, I do try to tell them there's a difference but I just don't know how long she's going to live for. I just feel really bad from inside, she is my daughter and I don't know why everything is happening to her, it's not fair.'

Family caregivers understanding the diagnosis of heart failure were sparse; of those family caregivers that could access information and resources themselves, did so by questioning healthcare professionals and by accessing on-line resources. However, of those family caregivers that were unable to comprehend exactly what the diagnosis meant, longed for explanations, as they were left feeling confused and saddened by their reality.

AS (daughter): 'I drive them up the wall by asking too many questions but I strongly believe that the more I ask in the process the more I will learn from it and the more questions I ask ultimately it will help me understand my mum's condition and to help her in the long.'

MN (daughter): ‘I think … in one way it’s made us really aware of the fact that my dad’s got it that we’re more prone to getting it genetically especially through the men and so like my brothers are very gym fanatics about exercise but … we are more aware of it and we try to modify our diet and exercise but at the same time there’s a lack of awareness because you think it won’t happen to you and it’s that ignorance I guess and there’s a detachment from it so you live your normal life because you think your still young and err … it’s like having someone with it in the family really makes you aware, I don’t know if it actually causes you to change yourself fully err … especially because I am the youngest I think but the older lot have taken it in to account and you know exercise and watch their diets and have their vitamins and constantly have their checks for cholesterol so yeah so it’s like double edge sword kind of thing but the next generation should exercise so hopefully they shouldn’t have to worry and have good diets.’

NM (daughter): ‘I think, I think just by somebody just … to talking to me and just explaining to myself how the heart works or what condition it is. I still don’t know, I am still in this confusion … exactly what happened to my mum, I still don’t know and whenever I go to the nurse they try to … I feel they don’t explain it the way I want them to explain it. I think when I have gone to the doctors or taken her, I’ve just picked up bits, bits here and bits there and I have thought okay, this is what’s wrong and I have just searched it on the internet and thought okay, but you still want answers don’t you. You want somebody to sit you down and talk to you.’

Feeling worried and concerned for the well-being of patients was a huge concern. Family caregivers felt very distressed and upset for a majority of the time. It was difficult to fathom losing loved ones who had been very much an integral part of the family’s life. In particular, one family caregiver tearfully described taking anti-depressant medicines to help cope with the diagnosis and challenges of heart failure. It was common for family caregivers to feel anxious and on edge throughout the day when engrossed in caring duties. The reality of receiving upsetting news was a fear that lurked constantly at the back of their minds as demonstrated below:

AH (daughter-in-law): ‘We don’t want to lose him, that’s the biggest worry in our life. He’s the head of our family and we love him to bits and we don’t want to lose him. I just pray to god he has a long life and he stays with us, he sees everything happening in my children’s life and he’s a part of my life (crying). I lost my father before I was born and he was my father, he’s done everything for me and I just don’t want to lose that. I will be losing my dad again if I … if that happened and I just want that (crying). I just pray to god that he has a long life and that everybody gets better.’

FY (husband): ‘I am feeling very sad since she has had this problem so I am keeping my eye on her because sometimes she forgets then she worries. There’s too much I am feeling, she’s my partner. I have to take care of her and she has to take care of me… this is the system between husband and wife. If something happens, what will happen to me, what will I do?’

GH (wife): ‘Yes, I do worry about it because together for 45 years (laughs) and I do get depressed, so I take tablets for it. I do worry that why I have arguments all the time because of the diets because I do worry. If he doesn’t walk for five years how will he walk because his joints and health and weight and body is not working because he’s not using the heart muscle and it becomes weak if you don’t exercise or walk for a month. I could climb the stairs so quick because I can feel that if I don’t use it I will get tired, this is for everyone but it’s been five and a half years … if he goes to the masjid that’s using the car, if he’s going shopping he’s using the car so I think it makes you illness more worse. It’s a lot of time because of the TV (laughs). He even tells me to not walk, he said don’t walk to me. Yes, I want to go out and exercise, I want to. It’s good exercise but he doesn’t support me. He doesn’t care; he cares for himself (laughter). All my life I am working, I am always in the kitchen or working. Oh my god, I don’t go anywhere … I am always in the kitchen so how can you live with a man like him? Yes, I do worry. It makes me really, really worried. I do worry. It’s in my mind all the time, all the time it’s bugging me. It’s really, really hard. I can’t do anything, I just keep going. I can’t sleep so I take the tablets, Alhamdulillah. I take them then I feel a little bit better and calmer but it’s hard you know … I am coping a little bit better.’

NM (daughter): ‘I’m very scared, really scared for her. I think when I go to bed I think I am going to get a phone call and yeah … that err … something has happened to her. It’s very, very difficult. I don’t talk about it usually, but it is very hard because you’re waiting for that phone call to come, yeah … every night. Yes, every day … every day even through the day time when I am at home you know if I am at home with the children I do not miss that call because I will want to know who’s called. I will shout at the kids and ask who has called and she might just call because she wants to go out but that fear in my, in my head just won’t go.’

Remembering the patient as their former self was strikingly different to their current status. Family caregivers described marked differences in the decline of health. As a result of physical health declining, family caregivers expressed how much had been taken away from the person they once knew. Heart failure and related co-morbidities prohibited and stripped away the independence, mobility and social drive of the patient making the life of a family caregiver very challenging as it prevented the family caregivers from being able to dedicate some time to their own selves. An example of these has been illustrated below:

AH (daughter-in-law): 'Life has been changed because my father in-law was a very independent person, he would love to do things himself and he used to like going to Pakistan himself, he loved his country so much. He tried to spend a couple of months here and a couple of months there because he liked to travel but since the heart attack he's been stuck in one place so he hasn't gone to Pakistan for seven years now. That independence has been taken away from him. If he wanted something he would go to the shops himself, he used to drive himself and then because he went out a lot, his eye-sight went bad because of the diabetes so the opticians said he can't drive because he can't see so it was everything slowly, slowly, everything just went away from him.'

Sources of support included healthcare professionals, family, faith, friends and on-line resources. Family caregivers accessed such sources to acquire help in the management of caring for someone with heart failure. However, in instances where minimal support was available or none, it was a huge struggle to cope with the lack of informed information which resulted in family caregivers feeling helpless, pleading for support resources. This would range from literature post-discharge to feeling 'alone' and at a loss, not knowing how to manage. Family caregivers felt unsupported and left 'in at the deep end' of coping. Furthermore, they felt isolated, guilty and inadequate for not being able to do enough within their role. This was further exacerbated by 'community members' judgment. Family caregivers felt they were failing in their role as a family caregiver. A major concern family caregivers highlighted was that they felt stereotyped in the care they received from health professionals highlighting the inadequacy of support tools made available. Below have been given examples of such experiences:

FY (husband): 'Yes, she's supporting me (wife) and I am supporting her. You see you can't clap with one hand, two hands will clap together.'

IB (daughter-in-law): 'Err … when she came out from hospital they didn't tell us much about what had gone on, when I did ask they would just say a little about what happened and then that's it you were just chucked in at the deep end to cope with it so no, we didn't get the helped we needed, we just cope with it. I think they need to explain what's going on more. The kids are at college, but that's not enough because you have to work around those times, I will make sure my appointments are around those few hours. It's a nightmare sometimes. If we get more hours at the day centre or an extra day there, others can get a break. Her lifting is becoming more difficult because you have to lift her which is becoming a nightmare because I can't lift her anymore, they think I might have cancer so I don't know where my life is going either, it just becomes too much you know. My sisters help me … they help me a lot if I need a break and if I want to go out then they will take me out for dinner or something like that so it's family, yeah.'

MN (daughter): 'I think the hospital themselves shouldn't discharge patients like this, they should give information packs or leaflets and nurses should come home and not fob off patients … I know that there is a stereotype that they are Asian and that they bring it on themselves which is I think completely wrong, especially in my dad's case. I can't answer for everyone but you know … you know, you can't put everything in the same field or categorises them, you can't because he couldn't do anything more even if he tried and you wouldn't get someone like him, you won't … he's willing to push himself to make sure he's healthy even though he won't be fully healthy so yeah they definitely need more awareness for the Asian community rather than pigeon holing everyone and then creating information and tailoring it because it's unfair, it really is because no offence I mean I have lived in both worlds but if you're in an area like X or X and your patient who is White you would be treated differently and we were, when we went to X we were treated differently to (X) with heart problems and it was just like … even the environment was stuffy and the chairs were old and at X, honestly it was spanking new and the nurses … everyone was treated great, as many visitors as you want so yeah, there's definitely issues there, deeper issues that need solving but just that the politicians. It is definitely … especially if you live in an area where the post-code is awful but there are differences. We live in this area because of the Asian shops and the mosque and we moved here from the north but you … the repercussions are poor because they don't treat you right, you're just another typical Asian.'

NM (daughter): 'I think … I think I had to learn about it myself. I had to learn about it myself, I wasn't told how you manage this or … I wasn't actually given that support at all. I had to learn myself through the internet. I think when I have gone to the doctors or taken her, I've just picked up bits, bits here and bits there and I have thought okay, but you still want answers don't you?'

Family caregivers expressed shock and disbelief when trying to digest the diagnosis of heart failure. It was described as an intense time when adjusting to the caregiving role which was both demanding and worrying. Nevertheless, families forged together to provide the best care they could making sure the patients' holistic care needs were being met. The daily routine faced numerous barriers ranging from contentions with dietary intake, exercise management, stopping smoking, medication adherence, prioritising self, meeting other family member needs, and meeting the expectations of patient and community members. Moreover, family caregivers would regularly find that they self-neglected and found themselves to be on many occasions unsupported by patients leading to feelings of deflation and low self-worth. The following statements have provided insight into such realities:

GH (wife): 'Yes, yes … I have changed the diet to my partner's diet. From the start, I decided because I have to eat with him because if I eat something different he will as well so I decided I will eat with him the same thing so it's easier for him to do so that's it. I think about this thing because this is … too much grease is no good for him or red meat. I tried to cut down even if he argued with me sometimes but I don't listen. I use less salt, he complains about it sometimes because there is not enough but I don't, he gets the salt from the kitchen and puts it on himself. He wants more salt and I will say 'no it's not good for you' and he wants meat all the time but it's not good for him. This is the thing and he doesn't want to go out, just watches TV 24 hours so I say you stay here and I will go out but then he will say why are you going and don't do that but I will go … sometimes I stop but sometimes I don't care but when I come back from the shop he will say 'dosser has come home now' (laughing). He will you go dossing even though I go for shopping.'

AH (daughter-in-law): 'Yes, he used to smoke a lot. I don't know how many maybe more than twenty he smoked, he was a heavy smoker … he used to be. We did everything, we took him to the doctors and get the patches and stuff like that and I got him patches and at the chemist you have a white err … what do you call them, nicotine cigarette you get and you put that a tablet inside that and I used to buy him that to help him stop smoking. I tried everything, I used to buy him loads of them and ask him to use them because if I got him those then he wouldn't use the cigarettes and harm him, and we tried everything.'

Recognition to the patient's recovery process was regarded with much appreciation. Symptomatic management improved greatly leading to a better quality of life. On the other hand, however, the care for a minority of patients was unfortunately declining greatly, worsening the quality of output which affected both the patient and family caregivers. The following examples have illustrated these points:

IB (daughter-in-law): 'Err … her mood swings, her screaming at night for no reason … and wanting to go to the toilet but then not going, I don't think she likes being on her own and err … you know very moody all the time and screaming all night. If she is up all night she will wake everyone else up and like eating, we've just eaten just now but then she wants more and it's loads of things like that and it's like everything has to run around her and not everyone else. It makes everyone's life difficult … yeah, sometimes she gets breathless and she finds it hard to breathe but then she has asthma too and recently the tablets that got changed seem to be working on her but before she wasn't able to climb the stairs when she was taking the old tablets so it seems to be working a lot better now and it seems like these new tablets are working on her.'

NN (mother): 'It's affected me a lot … before she had thalassemia and diabetes but with the heart failure I just don't know what is going to happen to her now, it has affected me a lot. Every night I just can't sleep because I am thinking what's going to happen (crying).'

The management of diet was a double-edged sword. Patients managed to make temporary changes but found they soon reverted back to known 'bad' habits leaving family caregivers feeling frustrated and upset. The preparation of meals, reducing portion size, eliminating fatty foods from diet and shopping for healthier foods became a common part of the family structure as family caregivers became conscious of leading healthier lifestyles for both patients and wider members of the family despite contentions as illustrated below:

RY: 'Thinking about when he was first discharged to now, do you think much has changed?'

KM (son): 'For a short period, yes. We tried to change the diet … but it's gone to back to normal I feel now, back to the old ways again. Well, just the fatty foods and sweet foods. He goes out and keeps buying sweets and he'll excuse his ways that he can't live without it. He will say he can't live without it, that's his general sort of ways. He's really fussy about vegetables, he's not a vegetable person and won't eat those and he won't eat the same food on the second day. He's fussy but that's his choice of eating… he eats three times a day basically but it's extra bits and pieces, he will go out and buy Asians sweets like matai that he will buy for himself … things like that those that really get to us because he knows how it will affect us, I don't know why he will go out and buy foods like that.'

MH daughter): 'Okay, I'm more conscious of the amount of oil and the exercise and trying to get the five a day and more water. I haven't gone drastic or taking things up 100% but more conscious, definitely more conscious of things. In the last four or five years we have started using sunflower oil and corn oil, that's the two we're using now, if we have meat three times we won't have it again, we look at what gets eaten in a week. We eat lentils, roti and that's fine and maybe fish pie in the day so we just look at what he's had in the week and if he wants samosas we will say no because he will have had meat earlier in the weak so we won't do it again, so that's the main thing we do and anticipate what to cook but oil is our biggest change … he likes more salt, he's more of a salty person and if a dish doesn't have enough he will put it in himself … yeah, we just literally work with what we have. He loves his snickers chocolate and if we don't give it to him he will find it himself so we would rather know what we have given him than to know there is a box of matai in the fridge.'

NM (daughter): ‘Yes, but not that much … she will say you want me to stop living, you want to take this away from me too, she eats what she wants.’

NN (mother): ‘I have to cook twice instead of once so I cook once for her and then cook differently for the family. I have cut out fatty foods now, before she would eat more take-out foods or fried foods and fatty foods but now she avoids them and I give her grilled foods and I have tried to stop the fatty foods because it’s not good for her.’

Physical activity was very much dependent upon the patient’s mood to want to engage in exercise and on their limited physical abilities. If possible to do so, family caregivers shared activities with patients, such as walking, gardening, encouraging and assisting attendance of cardiac rehabilitation. However, support was not always made readily available. In one instance a family caregiver expressed their reluctance in allowing and supporting their family member to attend exercise classes as there was a genuine concern that they may over-exert themselves despite the longing of the patient to attend cardiac rehabilitation. Contentions and frustrations also arose when patients refused to attend exercise classes and/or share activities due to laziness and in instances patients would hold back their family caregivers from keeping active. Such unsupported acts made it very difficult for family caregivers to feel positive, resulting in upset and deflated mind-sets. Such challenges have been illustrated below:

GH (wife): ‘He doesn’t want to exercise. I like to walk and he doesn’t want to do that … because for a long time he just wants to watch TV and sit down so that’s why he can’t exercise because he doesn’t move, he’s rotting away in the chair so that’s why he can’t move and walk because of the illness. I think he can’t walk because he doesn’t want to walk so that’s why this is why it is my problem. I like to walk, to go out and walk around and do the shopping or just even walk but he doesn’t like to do that because he loves TV and I don’t like TV … this is the thing which is causing arguments sometimes but I didn’t take it very serious to tell you the truth. He tells me why you are walking; he’s dragging me along with him. He tells why are you exercising your weight is okay because he’s like that.’

MN (daughter): ‘Initially my dad stopped doing everything like swimming and walking but in the last four or five weeks he’s started swimming again. He used to walk so he stopped it because of angina but because now he is saying his chest pains have gone he wants to start walking and he does get tired but the biggest worry for us is that will he collapse, we don’t want him walking by himself because he won’t take a phone with him even though he’s got one so you just don’t know what can happen so he’s trying to get back to his old routine which we don’t mind as long as he’s got someone with him so … in a ways it’s good.’

NN (mother): ‘Yes it’s because of her symptoms she can’t exercise; it’s too tiring for her. I do take her out to my sisters but she will stop on the way to rest, it’s only one road away.’

The management of medicines was a difficult task for family caregivers especially when managing multiple forms of medicines administration. The use of blister packs helped family caregivers manage medications as it relieved the stress and worry of adherence at allocated times and multiple medicines. In cases where the use of blister packs was not adopted, family caregivers reminded patients of their medicines or administered their medications themselves. Administering medication was a challenging time for family caregivers as the behaviours and attitude of patients were particularly difficult. Furthermore, family caregivers struggled when patients became careless with arbitrary medication adherence and when patients solely relied on medicines to control their heart failure as opposed to applying themselves to controlling other lifestyle risk factors. Contentions and frustrations also occurred when patients failed to inform family caregivers of their medicines running low in stock and reserve, thus the need for repeat prescriptions. Below are examples that have been presented of illustrations of such statements:

AH (daughter-in-law): ‘We used to do it at home, but he’s got a problem where he forgets very quickly so I went to my GP and asked for the blister packs where it tells you what to take so I got that for him, at least he knows which to take because he had a lot of medicines, about 19 tablets.’

The mother of NN struggled with her daughter who found it very difficult to manage medications. The patient being looked after was a young girl who had multiple co-morbidities and subsequently had a plethora of medications. Monthly blood transfusions for thalassemia in addition to tablets, insulin injections for diabetes and tablets for heart failure meant that a total of nineteen tablets were taken daily. This led to much frustration, upset and contention. Medicines management, in addition to managing other lifestyle risk factors, was a stressful and anxious time that impacted the role of the family caregiver tremendously whilst managing additional family members. An example of such struggles has been illustrated below:

NN (mother): ‘Yes quite a lot, there has been a lot of changes. I do supervise her and with her food and stuff … before she was bad with her medication and taking it but with supervision she has got much better … before being a teenager she wouldn’t listen to us, she wouldn’t take her medication, maybe she would take it once a day or twice a day and then wouldn’t bother. If I did tell her or her dad then she would just argue with us, she was careless but now she has realised that if she doesn’t do those things she is in danger. I do try my best, I really do … I bought those packs for her so she will know what she has taken on time but then she’ll take some and then leave some. I am trying my best.’

5.2 SUMMARY OF PHASE 3 FINDINGS

Phase 3 involved interviews with family caregivers post interviews with patients. Adjusting to the role of a family caregiver was a challenging task. It was a demanding role to adapt to as family caregivers offered their time generously caring for the patient resulting in less time for both themselves and other family members, whether that be spouses or children. Consequently, this exclusion was also an emotionally straining time as family caregivers slowly saw patients' health diminish and deteriorate. Family caregivers described the loss of role and stature the patients once had as a painful sight. It was difficult to comprehend patients losing their ability to carry out tasks for themselves and maintain independence. Therefore, adjusting to the diagnosis of heart failure and related co-morbidities was disheartening.

Understanding the diagnosis of heart failure and its prognosis was arbitrary as some family caregivers took it upon themselves to research on-line resources to gain knowledge or by asking and really 'pushing' healthcare professionals for answers and clarification as to what the diagnosis meant. Managing heart failure was a step-by-step process; it was attempted in small steps conquering medicines, diet, exercise, employment (family caregivers described the financial strain whilst patients were recovering); it became a strain to financially manage business and home duties whilst additionally caring. Specific struggles were highlighted when language acted as a barrier. The difficulties of communication meant that family caregivers found it difficult to 'take over' and manage their partners' businesses. Members of family took turns in caring, managing appointments, collecting prescriptions and food shopping, in addition to sharing activities of physical activity.

A combination of extended family members and faith were perceived as sources of support. Family caregivers described a lack of service support which left them uninformed and uneducated post patient diagnosis and discharge. A lack of information giving which would support patients to manage their lifestyle risk factors and make positive changes failed to be provided. Family caregivers expressed their wishes to be taught strategies on how to administer positive care and changes along with being informed what heart failure was and its causes as opposed to being thrown in at the deep end. Family caregivers felt they were judged for inadequately meeting the needs of the patient and extended family members. The judgment was portrayed through the community and extended family members. If it was perceived that the family caregiver had external family caregiver support or continued to carry out an activity for themselves, they were deemed selfish and inappropriate. Moreover, family caregivers felt they were stereotyped and categorised by health professionals as communities who were reluctant to change and adaptation due to their socio-economic status when in fact tailored guidance was what family caregivers craved. Family caregivers stressed living in ‘socio-economic’ deprived areas was a choice as the ‘community’ in which they resided brought amenities such as easy access to the Mosque and grocery shops that were permissible ‘halal’ choices. This was by no means a deterrent to making positive changes. A minority of family caregivers resorted to on-line resources to search for help and insight despite a judgment from service providers.

A real concern and worry for patients’ health and well-being left family caregivers feeling very scared and confused. Most family caregivers felt depressed and saddened, unable to cope with the physical, mental and emotional demands in addition to the worry of ‘losing’ and seeing their loved ones suffer and deteriorate. It was a difficult time to comprehend the person they once knew become heavily reliant upon family caregivers for all their needs. Managing heart-failure, its symptoms and co-morbidities became an exacerbated task as patients became difficult to manage within the home setting. Managing physical, emotional needs and the differing moods was a frustrating task at times, one which family caregivers responded to emotionally quite poorly, and the strains it set. Family caregivers described patients as stubborn, behaviourally restrictive and demanding. Though family caregivers thoroughly dedicated their commitment to caring, it became a burden at times especially when family caregivers felt they were spread so thin. Many mixed emotions took their toll upon family caregivers making it a challenging role. This left family caregivers feeling unsupported and low in esteem. Family caregivers spoke of taking medicines such as anti-depressants to help them through these anxious times as they felt mentally consumed by worries of losing their loved ones; this was a frightening prospect.

Making changes to lifestyle risk factors was exhausting for family caregivers as they found themselves balancing the patients’ needs and rest of the family’s too. Patients were reluctant to change, making simple changes a contentious time. Family caregivers found themselves preparing separate meals for the patients and then the rest of the family. Substitution for healthier choices and reducing portion sizes was adopted and, where possible, for the whole family including patients. A majority of family caregivers found that changes would be made short-term as opposed to lasting changes as they were not confident to sustain and maintain recipes that the whole family enjoyed or that patients would allow, therefore post a short-term basis the patients reverted to indulging in unhealthy options regardless of attempting positive changes and leading by example.

Physical activity was a task encouraged by most family caregivers and, where possible, shared. For example, walking and gardening was an activity most family caregivers shared with patients to help them become more active. Family caregivers spoke of restricted mobility acting as a barrier and for most patients this reality made it difficult to exercise. However, where patients consciously did not want to engage in activity and furthermore held family caregivers back from outdoor activity, family caregivers became frustrated and appalled at the two-fold restraint. Home comforts such as television and poor weather made it excusable for patients not to exercise leading to contentions with family caregivers who were frustrated at their attempts to encourage physical activity.

Family caregivers managed medications for patients using various strategies, including adopting the use of blister packs. Managing medicines was a very difficult task as patients occasionally refused to take them, displaying challenging behaviour resulting in contention. Family caregivers complained that when medicines needed a re-stock, patients deliberately withheld information of this making it difficult to renew prescriptions on time. Management of co-morbidities and smoking management were challenging. Efforts to reduce and/or quit smoking were successful using numerous methods with the help of health professionals. In addition to heart failure, managing additional co-morbidities and their related symptoms were a strain as they included challenging behaviours, increased hospital admissions, and increased poor prognosis and deterioration.

Family caregivers became more conscious and aware of their role as they settled into their role and thus made steady changes to their own and families' lifestyles. A change in attitude was a marker in making conscious improvements to bettering one's health and the families. Knowledge was empowering and this was welcomed. Family caregivers stressed the importance of this and highlighted the need for health professionals to show support and non-judgemental attitudes in making this happen.

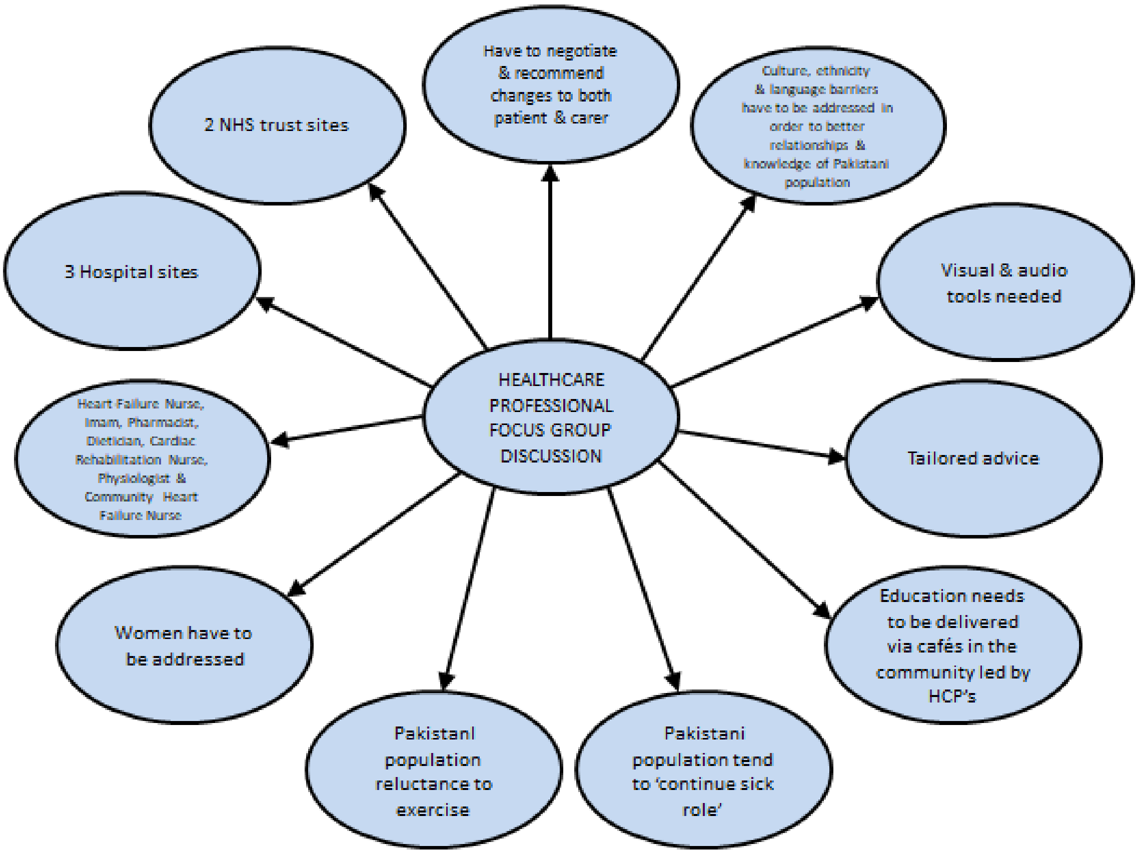
Language barriers made it difficult to manage the daily living of caring. Managing family businesses, financial agencies, occupational healthcare professionals and liaising with external agencies where communication was imperative was challenging as the burden of liaising with such bodies was foreign for family caregivers due to difficulties in language and communication.

Family caregivers pronounced a poor explanation of heart failure and its prognosis as they stressed that they had been 'thrown in at the deep end' of coping without effective knowledge making daily management challenging. Consequently, the management of lifestyle risk factors including medicines management, dietary management, physical activity, symptoms management, anxiety and depression were very difficult to comprehend and manage successfully.

Family caregivers highlighted the need for support in various forms. It was stressed that health professionals would deliver this in the form of educational tools which would heighten the education of heart failure eradicating the feeling of family caregivers being judged by healthcare professionals on their socio-economic status and cultural beliefs and values. Furthermore, personal support was longed for as they all felt a deep sense of a loss of role, self-neglect and feelings of fear and concerns regarding patients' health which led to anxiety and depression. Moreover, it would condense the feelings of judgment by community members who were labelling family caregivers as failures and inadequate in carrying out their duties. Support from professional agencies would bridge these gaps as it was hoped awareness would bring focused support.

6 CHAPTER SIX: FINDINGS – PHASE 4

Phase four highlights the perceptions and concerns of healthcare professionals through focus group discussions.



The following members were in attendance:

- Maulana Saab (Religious Pastor)
- Dietician
- Pharmacist
- Heart Failure Nurses
- Cardiac Nurses
- Community Heart Failure Nurse
- Gym Physiologists

Unfortunately, both a cardiologist and GP were unavailable to take part due to work schedule commitments. Furthermore, a psychologist was also unavailable due to the service not being in existence to patients and their family caregivers, but only to members of staff via an occupational health department.

An open discussion amongst a multi-disciplinary team stressed the challenges and struggles Pakistani patients posed to managing lifestyle risk-factors.

Physical activity was brought to the forefront during discussions, in particular the agreed consensus of reluctance to exercise and an extension of ‘continued a sick role’ for a length of time, delaying the recovery period. Healthcare professionals emphasised the reluctance patients showed when engaging in physical activity. It was agreed that restrictions to exercise did exist due to the inability to mobilise freely given symptomatic barriers. However, healthcare professionals emphasised the importance of physical activity to recovery despite the heart failure patient’s sickness.

Healthcare professions agreed that providing knowledge to patients was a sensible way forward that would attain changes. This would incorporate culturally sensitive and appropriate changes that would combine a cardiac rehabilitation regimen.

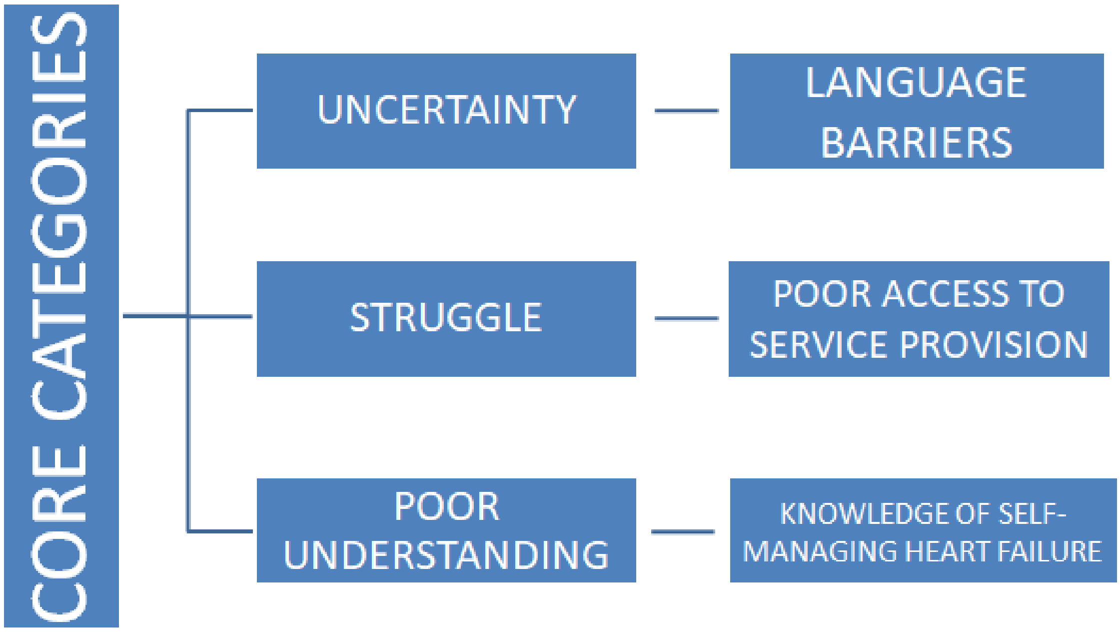
A multi-disciplinary team of professionals also agreed that women’s needs had to be addressed and understood to aid them in their recovery process. Culture, Ethnicity and Language barriers had to address better relationships and knowledge of the Pakistani population, especially the demands on the female population. Understanding and capturing knowledge of the Pakistani culture, ethnic background, language and communication barriers were deemed imperative to build stronger relationships with the Pakistani population.

Healthcare professionals put forward suggestions of both visual and audio tools that would be culturally sensitive pooling together the required information needed to assist in the recovery of Pakistani patients and their family caregivers. It was suggested that visual resources would aid knowledge of unanswered questions.

The suggestions put forward by health professionals and in specific pharmacy included visuals (pictures) of medicines heart failure patients would be prescribed to administer. Clear labelling of the names of medicines and furthermore, dossette boxes would also be presented. Audio information would include informing heart failure patients of dosage and storage methods of medicines in preferred languages.

Moreover, recommendations as put forward by a dietician included visuals of portion control and ‘Pakistani’ foods on a plate that were filled with essentials to the individual. This would also have varieties that would include healthier options of all food groups. The dietician felt it was important to include a palate that was desirable to the individual and inclusive of foods that were culturally appropriate. The community heart failure nurses expressed the need for audio information that would include highlighting the availability of translators at the participant’s discretion detracting the barriers of language. The community heart failure nurses conveyed the importance of providing support to participants, which would include breaking through language barriers with respect to opening communication channels. The Maulana Saab and physiologists again reiterated similar visuals and audio information that would showcase them within professional and community settings in their role would portray how they could facilitate in the rehabilitation of heart failure recovery. The gym physiologists wanted to convey the culturally sensitive message of attendance to physical activity by portraying images of both men and women at a setting which was safe, open to all and beneficial highlighting women only classes, the presence of chaperones and also offering classes to those who were in employment. The Maulana Saab understood the importance of his role and the weight it carried. Therefore, he felt that it was important to be both on hand in settings that were in the community and at work where participants could access such support. Visual representations of this and audio information providing such comfort and acknowledgement of support was highly advocated. It was proposed that audio information in collaboration with other health professionals would endeavour to show unity and importance of efficacy in healthcare management of heart failure.

The persistent and recurring references emerging through phases one, two and three of the study and subsequently the categories and sub-categories forming communicated and emphasised the over-arching core categories. The profoundness of the concluding details drawn out from the data merged the categories and sub-categories that interpret the emerging theory pertinent to the Pakistani heart failure population. This has been illustrated below:



6.1 SUMMARY AND CONCLUSIONS FROM GROUNDED THEORY ANALYSIS

This section has provided an overview of the research findings and a conceptual account of living with heart failure post discharge. The aim of the study was to describe patient and family caregiver experiences of living with heart failure. The grounded theory approach was utilised to uncover and categorise the major categories emerging within the data. Phases one, two and three highlighted the reality of living with heart failure from both the patient and family caregivers' perspectives. Phase 4 considered the perspective of healthcare professionals through focus group discussions. Although the aim of this study was to explore patient experiences following diagnosis of heart failure, participant responses led to the recognition that the experience of their journey was just one component of a two-phase sequence comprising the total heart failure experience. This ran parallel to responses from family caregivers alike. Further data emerged which amplified patient and family caregiver needs, which encompassed and addressed gaps to facilitate access to rehabilitation services.

The generated relevant grounded theory 'Battling the culture and ethnic sensitive obstacles of cardiac rehabilitation' was the emerging theory of the present study. Emerging from the current study was a substantive theory in which the absence of accessing culturally appropriate and ethnic sensitive tailored cardiac rehabilitation was identified as the main obstacle facing Pakistani heart failure patients and their family caregivers. These struggles acted as the basic social processes of how Pakistani heart failure patients and their family caregivers self-managed. The major categories and concepts underpinned and recognised the need for a negotiated pathway to self-management between healthcare professionals and the Pakistani heart failure patients. The process of recovery commands entwining culture, ethnicity and faith. Without the understanding of such imperative mechanisms in place, the functional rehabilitation and lifestyle development weakens the journey of the Pakistani heart failure patient and family caregiver. There was a genuine need to address the core categories of uncertainty, struggle and poor understanding pertaining to language barriers, poor access to service provision and poor understanding of pronounced knowledge of self-managing heart failure within the Pakistani community. These developing categories met the criteria of defining recommendations for a culturally appropriate tool by encompassing the needs of both patients and family caregivers, encapsulating their experiences of living with heart failure whilst recognising the importance of cultural definitions embedded within such a population.

The emergence of this theory added knowledge to the present study by promoting a better understanding of heart failure within the Pakistani population. Understanding and addressing the needs of this population have in turn provided efficacy in service provision empowering and enhancing the level of knowledge and management between patients, family caregivers and healthcare professionals. It was deemed that it was the responsibility of healthcare professionals working within the NHS services to work closely and collaboratively to deliver this appropriately in a culturally sensitive manner and consistently as needed and demonstrated throughout this study. This study has added a systematic way of linking this knowledge and understanding to the delivery of services and to the interface between target groups, Pakistani heart failure patients and their family caregivers and healthcare professionals.

It was imperative that initiatives were uniquely tailored to incorporate the cultural sensitivity as identified in this study in order to reap the effects and benefits of long-lasting change. While the implications for such sensitivity were similar to those suggested by earlier studies, the nature of the current study illustrated the persistent nature of cultural attitudes, community norms, socio-economic circumstances, and structural forces that acted as barriers to change in these ‘at risk’ communities, illustrated throughout this study. Examples of barriers identified through patient and family caregiver interviews and focus group discussions indicated how these might be used to inform health education programming and health policy-making at the individual, community and societal levels.

It was apparent that unless attention was focused on these factors, including deeply ingrained cultural beliefs, efforts to reduce heart failure disease and to improve better quality of self-management in ‘high risk’ groups were doomed to be limited. Further, clear links needed to be established between such specific initiatives and wider heart disease frameworks to ensure transferability of learning and integration within wider service provision.

A framework, in which an effective service provision was implemented, was an important aspect for those living with heart failure as both patients and family caregivers, because it bridged the gaps of unmet needs. The point when patients required most knowledge and care must be delivered at each stage in order to meet the needs of patients to ensure efficacy of cardiac rehabilitation. A stage by stage process must uniquely and specifically target, equip and structure actions to ensure consistency in informed care giving. Carving out the truth to meet the realities of self-management and understanding heart failure was imperative to both patients and family caregivers. Its usefulness of theory in practice must remain fluid in consistency and productivity. A tailored manual, which addressed the un-met needs as emerged from current data, must encapsulate ongoing cardiac rehabilitation care in the following stages:

- Admission
- Discharge
- On-going Management
- Family caregiver Management

Underpinning the foundations of effective cardiac rehabilitation was essential in-service delivery. The rapport of communication between patients, family caregivers and health service providers was better understood through this study as it addressed the deficiencies and identified the driving needs that would address improvements. Understanding the cultural and ethnic values of the Pakistani population allowed health professionals to work closely with patients and their family caregivers to bridge the gaps of barriers including language, service provision and service delivery. Conjuring these connections and shortcomings assisted in meeting these.

The overarching and fundamental theory of the study brought contribution of new knowledge that addressed experiences and subsequently the needs of the Pakistani population. The significance of the new theory for healthcare professionals was an insight into the gaps where their role specifically bridged the spaces in order to improve understanding and improve relationships with the Pakistani population leading to improved service facilitation. The findings from this chapter clearly highlighted that the journey and experiences of the Pakistani heart failure patient and family caregiver were different. Religion, ethnicity and culture played a central role, which influenced every aspect of the participants’ health and well-being. Religion was the core fundamental belief shared by all participants. Loss of role, lifestyle management (facilitators, barriers and adaptation) and symptomatic management were all a common phenomenon experienced by participants in addition to poor knowledge and understanding of heart failure and poor access to service provision. Adapting and making positive changes were a change short-term incorporation in the process of adapting to heart failure. However, in a majority of cases, health deteriorated due to maintaining an identity to the foods that were culturally of importance and value and the availability of foods high in saturated fats.

In the next chapter, the researcher has discussed in detail, the overall findings of this study to relevant literature that was built from extant knowledge. The researcher has provided an overview of the research findings and described both the patient and family caregivers' experiences of living with heart failure post discharge from hospital. A discussion of the researchers' experience has also been provided, including a description of the experiences of the research process. The strengths and limitations of the study have also been presented, and finally a conclusion has been provided encompassing a developed theory and a discussion of a conceptual framework, findings and implications for practice.

7 CHAPTER SEVEN: DISCUSSION

This section provides an overview of the research findings and a conceptual account of the Pakistani origin heart failure patient living with heart failure. The aim of the study was to describe patient and family caregivers' experiences of living with heart failure post discharge from hospital. This chapter discusses the findings from the study in comparison with the available literature.

The previous chapter explored the experiences and understanding of heart failure patients and their family caregivers. The researcher hopes that this piece of research will inform future health promotion interventions and strategies and help to provide culturally sensitive care for this large, heterogeneous group.

A grounded theory approach was utilised to uncover and categorise the major categories emerging in the data. Phases one, two and three highlighted the subjective reality of living with heart failure from both the patients' and family caregivers' perspectives. Phase four proposed the recommendation for an appropriate intervention to support patients and family caregivers in both a culturally sensitive and appropriate manner through the use of focus group discussions with a multi-disciplinary team of healthcare professionals.

A multitude of study reviews revealed findings that delved into the self-management of heart failure, functional and symptomatic status post procedure and discharge from hospital return to work, reduction of risk factors and quality of life (Gulanick et al, 1997). The exclusive exploration in isolation of Pakistani patient experiences and their family caregivers had not been reported post discharge across a two-phase continuum as in this study within the West Midland region. Pakistani heart failure patients have an increased risk of coronary heart disease-related mortality and morbidity. The present study found low levels of cardiac rehabilitation participation amongst the Pakistani groups (Galdas et al, 2012). This study identified prominent categories such as: physical activity, culture and religion, programme access and support structures, communication and language, dietary needs and medicines management which contribute towards effective cardiac rehabilitation. The following section will relate this study's key findings to relevant literature and discuss these in depth.

In the UK, the key health policy outlining the national standard for cardiac rehabilitation, the National Service Framework (NSF) for Coronary Heart Disease (DOH, 2010), stated that services should be accessible and acceptable to all the people they serve regardless of their ethnicity. This included ensuring staff and services were able to meet people's needs in ways that are culturally, religiously and linguistically appropriate and provided culturally appropriate advice about healthy lifestyle living (BHF, 2004). However, several barriers were identified to the equitable delivery of, and thus benefit of, cardiac rehabilitation programmes for South Asians (Sahni & Leslie, 2005).

Individuals of South Asian origin have a higher risk of premature death from coronary heart disease (CHD) compared with other ethnic groups; a pattern that has been recorded amongst South Asians residing in the Indian subcontinent and amongst South Asian migrants (Sheth et al, 1999; Yusuf et al, 2001; Gupta et al, 2006a; Joshi et al, 2007). The INTERHEART study (Yusuf et al, 2004) illustrated that established CHD risk factors including hypertension, hypercholesterolemia, diabetes mellitus, smoking and abdominal obesity accounted for more than 90% of the attributable risk of myocardial infarction (MI), regardless of ethnicity. However, there was evidence that abdominal obesity and insulin resistance, in particular, explained the excess coronary heart disease risk observed in South Asian people (Gupta et al, 2002, 2006a; Gupta et al, 2006a). The benefits of comprehensive cardiac rehabilitation for CHD patients were well documented. Meta-analyses of clinical trials showed net benefits from structured CR programmes included a 20%-26% reduction in total mortality and improvements in social and emotional health and well-being (Oldridge et al, 1998; Jolliffe et al, 2002; Taylor et al, 2004a).

Managing chronic heart failure was a daily challenge across all populations as many patients faced multiple struggles. This was consistent and shared regardless of ethnicity and culture. Therefore, it was important to not essentialise culture and marginalise chronic heart failure sufferers within categories that did not differentiate difficulties in coping experiences and behaviours (Culley et al, 2009). It is imperative that healthcare providers consciously delivered information that primarily focused on caregiving that endeavoured to answer questions targeting the needs of all populations in a more fluid manner.

However, the importance of cultural commonality that encapsulated a shared understanding was essential in assisting the needs of those less fortunate in accessing care. Targeted and functional provision, which reached entrenched historical roots and beliefs must be delivered to reduce disparities where appropriate if change was to occur for optimal improvement within the Pakistani population.

7.1 UNDERSTANDING DIAGNOSIS

Within this study, findings illustrated heart failure was a term that was poorly understood across both patients and family caregivers. A lack of confidence in knowledge and a high level of gratitude towards medical care highlighted a state of confusion, which resonated in unavailing satisfaction of on-going self-management. A majority of patients associated causes of heart failure to inevitable causes relating to family genetics, poorly led lifestyles and poor previous working conditions.

The underpinnings of such complacency existed in a high regard for a religious, cultural and ethnic stance whereby gratitude of faith overpowered the need to question healthcare systems.

Similarly, Lip et al (2004) identified that the levels of knowledge and perceptions of CHF and the treatments offered for this condition to patients who were attending heart failure clinics in two teaching hospitals within Birmingham, which served a wide multi-ethnic population were poor. Results showed that 64.7% (n=22) of South Asian patients felt that God/fate controlled their health whilst 35.7% (n=15) white patients felt that the greatest factor influencing their health was a health professional. A total of 68 patients of the total cohort of 103 patients (66%) were aware of their primary diagnosis. Half of the South Asian population (17 patients) felt that their condition was not severe in comparison to nine Afro-Caribbean and eight white population patients (40.9% and 19.1%). Of the study cohort, 38 patients (36.9%) were taking their medicines as it was a prescribed measure by their doctor, a common response of South Asian patients. A majority of South Asian and Afro-Caribbean patients felt that they did not know or have enough information concerning their medicines and a minority of the Afro-Caribbean patients felt that they did not adhere to their medicines, contrary to the white population who felt that they were informed of their medication (21.4%/ n=9). This study highlighted a serious deficiency in the knowledge of HF amongst patients from ethnic minorities (sic); it demonstrated a need for further investigation.

Functional self-management displayed itself to be a daily struggle. The symptomatic status made it difficult for patients to lead lives that would disengage them from inactivity. A continuation of lack of activity in the form of exercise or mobility continued to interfere with daily tasks. Exacerbations of symptoms were also related to co-morbidities. The cultural and ethnic thread underpinning the symptomatic status was fuelled by the continuation of a ‘sick role’ patients led. Counteractive to this, female family caregivers provided care on demand to patients.

Within previous studies, a few researchers had de-segregated their data by ethnic origin to describe what might best meet the needs of minority populations. This study addressed the issues of uptake of and compliance with cardiac rehabilitation by Pakistani patients and addressed the need to support the development of a culturally sensitive and safe cardiac rehabilitation programme. These findings would help health professionals develop guidelines for the design and delivery of a culturally competent cardiac rehabilitation programme for the

Pakistani population. Important considerations related to physical exercise, language and communication preferences, religious and cultural needs, dietary requirements, medication adherence and programme access and support structures, needed to be addressed in a culturally relevant and culturally sensitive manner to enhance the uptake and efficacy of cardiac rehabilitation for Pakistani individuals.

7.2 MEDICINE ADHERENCE

In this study, the doctor was perceived to be the most important source of information. Having trust in the skills of the medical professional prescribing medicines was a reassuring aid which decreased fears of medicine adherence (Gulanick et al, 1997). Pakistani heart failure patients continuously stressed their gratitude to having access to first grade medicines which they would not have had if they were living in Pakistan. Patients highlighted a poor understanding in knowledge of the multiple medicines they were prescribed (See Appendices 11.23). Heart failure patients felt unsure of the risks their medicines carried and the purpose they served. Furthermore, a genuine concern also worried participants as to how to store medicines. Subsequently, a majority of respondents collated their medicines in various carrier bags to help them regulate to adherence. In addition, heart failure patients relied heavily upon the support of family caregivers. Lack of informed professional knowledge resulted in heart failure patients self-adjusting to the administration of medicines during the month of Ramadhan which suited the times of fasting. Further evidence of this adjustment arose when heart failure patients felt overburdened with mobility issues. For instance, medicine intake was reduced to avoid usage of climbing stairs which would acerbate mobility challenges. Specific advice relating to adjusting medicines was not sought but patient led; clearly, this was an important factor in medicine compliance and one which must be addressed by health professionals if patients were adjusting medicines strategically (Boath & Blenkinsopp, 1997; Morgan, 1996; Rogers et al, 1998).

Concerns were also raised around worries of quantity of medicines and side effects. Adherence to prescribed medical interventions was an ever present and complex challenge, especially for patients with long-term chronic illnesses (Horne, 1997; Haynes, 1997; Pound et al, 2005). With increasing numbers of medications shown to do better than harm when taken as prescribed, low compliance was a major problem in health care (WHO, 2003; Pound et al, 2005).

It was clear from the findings within this study that compliance must be patient centered with the patient’s agreement and harmony in the doctor-patient relationship (Russell et al, 2003). The patient as a decision maker may thrive in empowering themselves to a better adherence regimen when informed choices were undertaken. Medical non-compliance has been identified as a major public health problem that imposed a considerable financial burden upon modern health care systems including multiple hospital admissions (Horne, 1997; Morris & Schulz, 1992; Donovan & Blake, 1992; Donovan, 1995). Compliance to treatment was a key link between process and outcome in medical care (Urquhart, 1996).

Adherence was complex and poorly understood. Patients throughout this study stressed inadequacies in their knowledge. Labels were associated by description of colour of pills and recognition of packaging. The names of medicines were not clearly understood nor their purpose (Ens et al, 2014). Medicines were kept and stored in carrier bags and deep concerns over the quantity of medicine consumed and side effects were a major worry. Further adherence research must focus on the extent and determinants of patient fears with a view of creating strategies to improve adherence and understanding (Donovan, 1995; Russell et al, 2003). It was essential that a patient centered approach was applied to the understanding of both doctors' and nurses' prescribing practice if regimes adopting complexities, unresolved concerns, fear of adverse effects and poor communication were to be understood (Donovan, 1995; Russell et al, 2003; Pound et al, 2005). The health professional relationship was an important variable in compliance, including the process of prescribing (Marinker, 1997).

Further investigation into the most salient influences on compliance must include patients' beliefs, attitudes and knowledge about medications (Marinker, 1997; McGavock, 1996). The knowledge of patients' own beliefs, ideas and experiences, as well as those of family members and friends, have been shown to correlate with compliance (Marinker, 1997; DiMatteo, 1994; Roberson, 1992) and such insights must be adopted to underpin medication compliance. It was important to know what sense individuals made of the advice given to them. When they arrived at the consultation, patients held sets of beliefs and theories about health and illness (Donovan et al, 1989; Stockwell & Schulz, 1993).

Medicine adherence seemed to be related to the quality, duration and frequency of interaction between the patient and doctor (Blenkinsopp et al, 1997a). The doctor's attitude towards the patient and his ability to elicit and respect the patient's concerns, to provide appropriate information and demonstrate empathy were of the utmost importance (DiMatteo, 1994). While a number of research articles emphasised the fact that patients made reasoned decisions about their treatment, others concentrated on the passive role that patients played in non-compliance (Stockwell & Schulz, 1993; Donovan et al, 1989).

Better compliance depended on doctors' friendliness and approachability, encouraging doctor–patient co-operation, the enhancement of patient-centeredness, the improvement of doctors' teaching skills, the considering of spiritual and psychological dimensions which might be of primary importance to patients, and the accurate recognition of the patient’s problem by the doctor (Donovan, 1995). Describing the effects of treatment could also significantly affect patients’ confidence to adhere to better patient education, aimed at improving patients’ understanding of their treatment and their doctors’ instructions, were suggested as compliance enhancing (Donovan, 1995). Other possibilities lay in the types of medication prescribed and techniques that encouraged patients to take the correct dosages. Simplifying prescribing, prescribing fewer concurrent medications and the development of longer-acting preparations might lead to simplification of the therapeutic regimen, but might not necessarily improve compliance rates unless the complexity of the regimen was one of the patient’s concerns.

Practical compliance aids included organisers and reminders such as blister packs, calendars, dosage counters, special containers, dosage forms, controlled delivery and microprocessors. Adequate labelling and written information and oral information provided by pharmacists might also help (Steiner & Vetter, 1995). Collaboration between patients, consumer groups, pharmacists, doctors and other health-care providers might enhance shared decision-making, possibly leading to better adherence (Morris & Schulz, 1992).

A coaching and non-judgmental approach and an examination of what could be achieved by the patient seemed to improve compliance (Mullen, 1997). This suggested that a menu of compliance-enhancing strategies might be needed in order to select an appropriate strategy for an individual patient and treatment. It had been suggested that training patients, as well as doctors, in communication skills might be a cost-effective way to increase compliance and improve the overall health of patients (Cegala et al, 2000). Knowing each patient’s health beliefs was the key feature of the new doctor–patient encounter. This might lead to a negotiated informed treatment plan to which both patient and doctor could adhere. This study undertaken made some comparisons to existing literature, which highlighted several similarities across all patients regardless of race, culture and ethnicity (Stone et al, 2005). In viewing medicines, adherence was primary to the effectiveness of any health regimen. There was a need for an awareness of the complexity of social and cultural experiences and attitudes in target communities. The results from this study have shown that patients with chronic heart failure have demonstrated a strong desire to live as normal a life as possible despite the descriptive strength and fear of the unknown.

Assessment of personal and circumstantial elements that affected adherence could be useful in developing more effective individualised treatment plans for this population. A closer look at discrete events of non-adherent decision making might indicate effective ways to promote adherence. Planning healthcare availability through a multitude of channels, including outreach clinics and community heart failure nurses, would assure patient continuity and decrease the patient’s vulnerability and enhance their valued independence maximising skills for optimal self-management.

7.3 PHYSICAL ACTIVITY (EXERCISE)

Within the present study, exercise was an activity that was deemed valuable by both male and female heart failure patients. The female gender specifically, expressed a heightened interest in participation as compared to the male population. Unfortunately, the Pakistani woman’s role within the home acted as a barrier to be as active as the women wished. The demands and duties within the home, poor weather conditions, transportation costs and family caregiver role restrictions and/or it being culturally taboo for women to participate within cardiac rehabilitation, meant that women generally fell short of maximising the up-take of physical activity and thus lost out on the benefits of a cardiac rehabilitation programmes. Furthermore, family caregivers were shown to restrict heart failure patients from engaging in physical activity out of concern for over exertion; this was specifically seen in mother-daughter relationships. Conversely, a minority of patients also held back family caregivers from leading healthier lifestyles based on their beliefs of mediocre outcomes of leading healthier lifestyles. This was apparent in males (husbands) and females (wives).

The attendance of cardiac rehabilitation by male heart failure patients was seen as an enhancement to lifestyle change. Family members and community friends supported activity which would benefit the patient. Male patients received more family support during their period of rehabilitation, whereas the female patients attempted to modify their lifestyle with limited help (Astin et al, 2008). Female family caregivers felt unsupported and discouraged when showing interest in the participation of physical activity. Family caregivers felt life revolved around the schedule and needs of the patient which put their needs at a lower priority. Moreover, female heart failure patients highlighted the importance of clothing choices and a single-sex environment, which favoured the likelihood of accessing and attending physical activity classes (Visram et al, 2008). Symptomatic disability was the only valid interruption not to partake in exercise programmes and where this was a restrictive barrier, patients were unable to take part in physical activity.

Jolly et al (2004) focused on the reasons for CR attendance of ethnic minority patients in the UK and also found that physical exercise requirements deterred some South Asian people from attending or adhering to a hospital-based programme. Participants who had declined to attend or who had dropped out of the CR programme cited various reasons, including being too old to exercise, feeling no immediate health benefits after taking part in exercise and having more exercise forced on them than they felt able to do. Interestingly, a unique study in this body of literature, a randomised controlled trial by Kuppuswamy et al (2009), found that patients attending a ‘culturally competent’ CR programme (the components of which were not described by the authors) derived greater physical benefits from the CR intervention compared with those attending the standard programme. Furthermore, the participants were more likely to continue to exercise following completion of the culturally competent programme compared with the control group (Galdas et al, 2012). Astin et al (2008a) compared the role of family support with regard to CR and lifestyle modification amongst South Asian and White-European cardiac patients. There appeared no major differences in CR uptake between the two groups. The researchers found that, compared with White-European families, South Asian families were less inclined to encourage their family members to participate in regular exercise as recommended by CR programme providers (Astin et al, 2008). Two other studies had shown that South Asian women were less likely to attend CR compared with South Asian men and ‘white’ patients of both sexes (Jolly et al, 2004; Banerjee et al, 2007).

A study by Visram et al (2008) found the experiences of exercise-related barriers amongst Bangladeshi and Pakistani women were poor. Female participants lacked motivation to exercise on their own and initially lacked the confidence to take part in the group exercise activities offered as part of the CR programme. Similar findings across the South Asian community were reported with Galdas et al, (2012). Darr et al, (2008) further added that no single female South Asian interviewee as part of their study had ever used exercise machines or joined a gym in stark contrast to the majority of European women in the study. It was reported that women were reluctant to exercise outdoors and unaccompanied because they found it difficult to identify safe and suitable walking routes in inner-city areas (Darr et al, 2008). Participants in Visram et al’s (2008) study were further noted to be embarrassed by some of the issues covered in the cardiac rehabilitation educational sessions, such as the advice provided about sexual relations, content that was considered to be ‘culturally insensitive’ and ‘inappropriate’. Chauhan et al (2010) found that mixed gender classes were problematic for Muslim women because of their cultural expectations and their religious practices such as the need to wear appropriate clothing in mixed groups, as well as the embarrassment of exercising in front of others (Chauhan et al, 2010; Galdas et al, 2012).

7.4 DIET AND WEIGHT MANAGEMENT

Eating a healthy balanced diet was essential in maintaining a healthy weight, controlling symptoms and having more energy. It was advised to aim for three balanced meals a day with healthy snacks in between. It was key that a minimum of five portions of fruit and vegetables were included in addition to starchy carbohydrates (bread, chapatti, potato, rice, pasta as all are examples of starchy foods that provided a slow release of energy), lean sources of protein (fish, lentils, eggs and unsalted nuts) and meat and poultry. Low fat choices should have been replaced where dairy and sugary snacks were concerned, also reduced in-take of saturated fats and sugars.

Weight management was essential in controlling symptoms. Reducing the amount of salt (2.5grams), watching the amount of fluid intake (2lt) and regular weigh-in sessions helped with sudden weight gain for a heart failure patient. Weight gain in heart failure patients might be due to water retention so it was important to weigh daily approximately at the same time to monitor fluid retention changes.

Within this study, dietary management was a difficult part of lifestyle management. For a minority of patients, eating became a time of panic and worry as those with multiple co-morbidities struggled to consume foods that would impinge on controlling diabetes for instance. Eating healthier meals, reducing salt in-take, reducing portion sizes and substituting healthier choices were a lifestyle choice that was adopted. Reducing the intake of oils, sugars, and fried foods was adopted and substitutions such as more fruits, vegetables, salads, white meats and fish were incorporated. Pakistani heart failure patients refused to give up ‘their own’ foods which hindered changes and caused many contentions in adopting healthier strategies. It was reported that the diagnosis of heart failure left patients feeling empty, resulting in loss of control and emptiness, thus control and enjoyment of eating what one wished was a joy that could not be substituted or left without. Taking the advice of personal trainers and taking guidance in dietary advice to keep control of weight and food intake were important and adopted by only a minority of heart failure patients. Managing diet and weight post discharge was positive in the short-term period. However, attitudes soon reverted back to eating what one liked thus making no long-term changes. Portion control, substituting and avoiding certain unhealthy foods were again something that lasted only for short periods of time.

Family caregivers struggled to break through to heart failure patients who dismissed the adoption of a variety of foods and healthier options causing contentions. Family caregivers communicated the difficulties they endured whilst persisting with change. Family caregivers conveyed they desperately acknowledged the changes to lifestyle they wished to prioritise with the heart failure patient, but the lack of compromise dismissed the value of change leading little or no development. Such disheartening advances grieved family caregivers extensively.

The preparation and consumption of foods that were culturally ingrained to the individual's life was an important aspect of the heart failure patient's life as it resonated with 'them' and 'who' they were; it was an identity that mattered to the Pakistani individual. Foods that originated from deep rooted cultural heritage were of significance and value that remained close to the heart failure patient. Pakistani food such as chapatti and curry were 'our' foods and this at the expense of change or substitute was seldom considered. A strong affiliation to the culture of Pakistani foods and the satisfaction this served to the Pakistani individual fulfilled who they were. The use of rich and traditional ingredients to conjure such palettes was a trademark of the Pakistani dish; it was what Pakistani food was. Red meat and ghee especially were traditional ingredients in the method of cooking and one that was inclusive of daily meals as part of the Pakistani palette. The ownership of this diet provided satisfaction two-fold: it gave control to be able to eat what was of cultural importance and secondly the enjoyment of a Pakistani dish remained close to the heart failure patient keeping intact their identity. Therefore, utilising this information and addressing the cultural importance were driving forces for health professionals that would lend support to meeting these needs sensitively in a culturally appropriate manner.

Lawton et al (2008) discussed the importance of food and eating practices from the perspectives of Pakistanis and Indians with type 2 diabetes. A qualitative study explored the perceptions of the barriers and facilitators to dietary change in addition to the social and cultural factors informing their accounts. It was found that despite considerable diversity in the dietary advice received, participants offered similar accounts of their food and eating practices following diagnosis. A majority of participants continued to consume South Asian foods, especially in the evenings, despite their perceived concerns that these foods could be 'dangerous' and detrimental to their health status. The authors stressed that participants described such foods as 'strength-giving' and highlighted a cultural expectation to participate in acts of commensality with family and community members deeming food an integral aspect of their culture and ethnic practice.

There was a perception that South Asian foods comprise 'risky' food options. This misconception needed to be tackled amongst patients and healthcare providers. To enable Pakistanis to manage their heart failure status and identity simultaneously, guidelines must promote changes, which worked with their current food practices and preferences; specifically, through lower fat recipes for commonly consumed dishes. Information and advice should be targeted at those responsible for food preparation, not just the person with heart failure.

In order successfully to promote ‘healthier’ food choices, health professionals must first understand how the Pakistani community classified and selected the foods they consumed. The exploration of food beliefs, choices and classification determined by cultural influences were essential to understanding decisions. Religious restrictions on particular food items, chiefly the Islamic prohibition of pork, and widely held ethnic customs based on ethnic patterns and methods of cooking must be perceived to alter the nature of the food. Dietary advice should be targeted specifically to reflect religious restrictions, ethnic customs and the different cultural meaning of particular foods, whilst also acknowledging the ability of the individual to exercise choice within those broad limits. This was fundamental for the design of health education messages.

This study, through the use of focus group discussions, highlighted the views of healthcare professionals as respecting and acknowledging the importance of cultural beliefs and agreed that a mutual understanding to recognise the needs of participants was essential in giving back control to participants and moving forward in healthy eating. Healthcare professionals agreed that priority must be given to participants’ concerns, as it was the only way to make progress collectively and effectively. The inclusion of foods that were of cultural importance were acknowledged by dieticians as a way to compromise and give patients back the control they desired incorporating healthy methods to be discussed at appointments when mapping dietary plans.

It must be noted that despite healthcare provider efforts and good intentions, the current study’s findings of patients’ experiences were inconsistent with healthcare professionals’ ability to assimilate cultural beliefs into their work. The most apparent differences presented themselves in the way of participants’ lack of understanding and knowledge of their health status and emergence of an informed inability to effectively self-care led to pronounced poor understanding, struggle and uncertainty. Subsequently, this emphasised multiple strains the Pakistani community faced when accessing service provision.

Self-management education was at the forefront of addressing the increased prevalence of chronic diseases. For those at greatest risk, such as minority-ethnic and/or socio-economically deprived groups, self-management education must be culturally tailored to encourage behavioural change. However, the application of culturally appropriate material and expertise within health promotion services continued to be debated. Sidhu et al (2015) qualitatively explored the experiences of healthcare professionals delivering a culturally tailored programme to culturally diverse communities managing chronic diseases. The authors found educators felt part of the local community, relating to attendees from different races and ethnicities. However, parallel to this, challenges arose when addressing health beliefs and changing lifestyle practices. A majority of communities were deeply ingrained in practices that were difficult to reform. Nevertheless, culturally tailored components aided communication, with educator's cultural awareness leading to close relationships with attendees whist delivering self-management education emphasising that the interpretation of being from the 'community' linked with the identity and status of the lay role, overlapping notions of race, ethnicity, and language. Sidhu et al (2015) concluded on a crucial note that affected many healthcare providers, that the development and training required for such roles were inhibited by financial and time constraints at policy-level.

There had been some research on the relationship between CHD and diet amongst South Asian people (Darr et al, 2008) and on how this relationship was maintained amongst South Asian women in particular. In general, South Asian patients were less likely to modify their diet than White-European patients. There were some noticeable differences between South Asian women and South Asian men, and also between South Asian women and White-European women. For example, South Asian women were less likely to recognise the need for them to lose weight than South Asian men. This was in contrast to the White-European population where women were more conscious about weight than men. Similarly, both South Asian women and men appeared to be more hostile to the idea of modifying their diet for the sake of their health than the White-European population.

Several reasons for this hostility have been suggested. Heo et al (2009) categorised the decisions to follow or not follow a specific diet into four main factors: knowledge; social pressure and encouragement from others; social situations; and food as a source of pleasure and enjoyment. In terms of knowledge, Heo et al (2009) found there was a general lack of knowledge amongst South Asian patients about what constituted healthy and unhealthy foods (Hunt et al, 2001; Remme et al, 2002; Lichtenstein et al, 2006; Uretsky et al, 1998), such as good fat and bad fat and appropriate sodium intake. On the other hand, Farooqi et al (2000) found that the vast majority of patients had some awareness of what constituted a healthy diet. There were also some common misconceptions amongst South Asian people that since their earlier ancestors did not struggle with CVD then the food, which had been passed down for generations, could not be the cause of heart disease. Another misconception was that the absence of meat in vegetarian diets was healthy and a protective factor for CVD (Patel et al, 2012).

There appeared to be a lack of a support network to encourage South Asian women to maintain a diet (Heo et al, 2009; Sriskanthantharajah & Kai, 2006). As a result of this, South Asian women had less of an incentive to make changes to their diet. Similarly, social situations also affected the feasibility of South Asian women to maintain a diet. Even if dietary adaptations were made at home, it was challenging to maintain this diet consistently outside of the home when visiting friends or when attending social events. Heo et al (2009) used the example of limited availability of low sodium food choices at restaurants and of difficulties finding appropriate foods when visiting others. Finally, many patients found it challenging to modify their diet because of the pleasure they derived from eating certain foods and so for some people, the pleasure of eating food was more important than the health benefits of changing their diet. According to Patel et al (2012, p. 780), ‘food is a central component of South Asian social gatherings and is another manner in which South Asians preserve cultural ties to their homeland. At these gatherings, it is considered unacceptable to turn down certain foods, increasing the struggle to maintain dietary change’.

There was evidence in the literature, of health professionals delivering cardiac rehabilitation interventions in a culturally insensitive manner. Participants in Visram et al’s (2008) study considered that conventional Western dietary advice was inappropriate when cardiac rehabilitation project workers had little knowledge of the standard South Asian diet (Galdas et al, 2012). Dieticians offended participants by recommending the eating of a vegetarian dish, dhal (dish consisting of pulses such as dried beans and lentils): a meal the participants considered was for poor people (Visram et al, 2008). This finding was consistent with evidence of the benefit of providing South Asian CR attendees with practical, culturally relevant dietary advice rather than merely translating Western/Euro-centric health promotion recommendations (Galdas & Kang, 2010). The promotion of a palette, which was applicable to the Pakistani culture, was advised depending of the individual’s desire, norm and style of eating.

7.5 CULTURE, ETHNICITY AND RELIGION

Culture, Ethnicity and Religion were pertinent to underpinning the foundations of the Pakistani heart failure patient’s self-management. It was the essence of these ingrained factors that individuals used to build their self-care and management of cardiac rehabilitation. Understanding the importance and distinctiveness of these would help determine how to model efficacy of rapport between this population and health service professionals and improve experiences of living with chronic heart failure. Patients and family caregivers throughout their journey of living with heart failure intertwined and merged these factors immersing themselves at the core. Intersecting these key factors encapsulated solace and restored balance to participants continually through prayer, Ramadan, and places of worship where community amenities secured comfort and knowledge working towards fulfilling the holistic self with a view of managing cardiac rehabilitation effectively. A fatalistic perspective was a common theme amongst patients in this study. Common phrases such as ‘it is up to God’ or ‘only God knows’ were used (Chauhan et al, 2010b; Darr et al, 2008) similarly found that South Asian participants were more likely than those of European origin to contextualise their heart disease in relation to their religious beliefs. However, in contrast to previous findings, although some individuals thought that they had little control over the onset of their illness, they were still willing to make changes to their lifestyles to improve their health and to safeguard against further problems. They considered their illness to be an indication from God that they had not looked after their health (Darr et al, 2008).

Kuppuswamy et al (2004) highlighted the potential benefits of a cultural and ethnic-specific cardiac rehabilitation programme, including improved patient adherence. The authors found that the adherence of their intervention group (the ‘culturally competent’ programme participants) was 21% greater than that of the control group (70.6% vs. 49.7%; p = 0·002). This finding was consistent with some qualitative studies that reported cultural and religious issues as key factors in South Asian patients’ cardiac rehabilitation uptake and compliance with recommended lifestyle changes. For example, the narratives of the Gujarati Hindu participants who were interviewed in Webster et al’s (2002) study highlighted that their MI and recovery from it were tied to fate or the ‘will of God’ and out of their direct control. This fatalistic attitude toward recovery from CHD, or external locus of control, reduced the perceived control participants had toward their rehabilitation and was considered by the researchers to explain the low adherence to suggested lifestyle changes and CR advice (Webster et al, 2002; Galdas et al, 2012).

Galdas and Kang (2010) also identified faith, religion and the Sikh tenet of Kismet (fate) in particular as key influences on the perceptions of their cardiac condition by Punjabi Sikh CR attendees. However, akin to the theme identified by Darr et al (2008), their participants were found to reconcile their belief in Kismet with a sense of personal responsibility aligned with the Sikh philosophy of Dharam dee Kirat Karnee (responsibility for one’s self) to make recommended healthy lifestyle changes (Galdas & Kang, 2010).

7.6 FAMILY CAREGIVER ROLE

A family or informal family caregiver was an individual who aided a family member or friend who was experiencing difficulties due to physical, emotional and/or cognitive impairments, often without financial compensation (Bridges, 1996). There were approximately six million informal family caregivers in the UK, with as many as three in five likely to become family caregivers in their lifetime (Carers UK, 2003).

UK Government census statistics pointed to significant variations between ethnic groups in terms of frequency and extent of caregiving. For example, individuals from White-British and British-Indian ethnic groups were most likely to be providing care at home (10% from each group), as compared to Chinese (5.8%), Black African (5.6%) and mixed ethnicity individuals (5.1%). British-Bangladeshi and British Pakistani caregivers reported spending the most time per week providing care, followed by White-British caregivers (Parveen et al, 2011).

Gender roles typically depicted culturally an acceptability and favourability towards the male gender. Male patients were expected to have and receive great care from their caregivers. Conversely, female patients received a low level of care, less provision and attention within their family environment of informal caring. The strain associated with the role of caregiving was vast. Wallace Williams et al (2003) found in their study of 148 African-American females who provided care to elderly family members a higher depressive symptomatology. The authors highlighted the valued importance for service support that provided caregivers emotional well-being.

Within the Pakistani culture, it was deemed the female caregiver would provide an expected duty and take care of their partner’s needs in addition to the needs of the extended family without prioritising self (Katbamna et al, 2001; Lawton et al, 2008). The burden of this pressure and strain were largely under-researched. The current study has demonstrated an immense amount of strain this role placed upon the female family caregiver; it was one that led to feelings and diagnosis of anxiety, depression, guilt, lack of self-worth and emptiness. The female family caregiver was submerged with multiple roles and responsibilities including marriage, offspring, community and extended family members in addition to caring duties leaving minimal time for herself. The merging of understanding the culture and service delivery support was a recommendation that needed to be adopted in the hope that alleviation of pressure was sought and provided to prevent the over-bearing burden. It was hoped that such training would support and provide caregivers with an equipped amount of confidence and courage to cope and manage chronic heart failure.

Essentially the responsibility of the caregiver role was entwined with immense burden and responsibility. This was conjoined with judgement from extended family members and community members who regarded the caregiver role as a natural progression of expected duties. The present study saw evidence of this. Caregivers felt heavily burdened with the obligation that fell upon them to manage their ‘expected’ role, especially daughters-in-law who had multiple roles to fulfil. The duty of caring imposed significant stress towards the role of caregiving. Performing daily medical tasks, dispensing medications, refilling prescriptions, attending doctor’s visits, hospitalisations, cooking and taking care of personal needs were only a few of the activities taken on by caregivers. The burden of these tasks placed stress on the self, marriage, and wider family. This was considered a low priority.

In the present study, family caregivers felt imprisoned as they struggled with the long-term functional distress of managing heart failure patients who refused to commit to change and who made little or no effort to comply with engaging to positive lifestyle management. Family caregivers stressed a tiring and exhaustive routine which heightened the pressures of fulfilling and meeting the needs of those around them whilst neglecting self. The absence of support and informed knowledge brought much distress to the family caregiver resulting in either falling deeper into over-burdened and un-dealt isolation or seeking external involvement. In instances where medicinal support was sought, anti-depressants and relief for anxiety were offered on prescription to the family caregiver in addition to respite, which included provision for residential support. This helped relieve family caregiver burden, a taboo within the Pakistani community and culture.

Anum & Dasti (2016) explored the relationship of caregiving burden, spirituality and psychological well-being of parents of Pakistani thalassemia patients. Their study indicated that the caregiver burden was negatively correlated with the psychological well-being and the domains of spirituality. The authors' identified that caregiver burden had direct effect on the psychological well-being of the parents of the children for whom they were caring. The study highlighted the role of spirituality upon the psychological well-being of caregivers, which could be utilised to prevent pathological influences (such as hard feelings, hopelessness, and depressed mood, anxiety, and relationship problems) of caregiver burden and enhanced psychological well-being through spiritual counselling in order to focus on well-being.

The Pakistani culture placed an assumption that a female family caregiver would fulfil the role of taking care of participants with chronic illness. The present study found that caregivers felt constrained with cultural expectations of the care role. This must be addressed to lighten the unrealistic burden that was currently placed on caregivers. Whilst, the responsibility was perceived to be a natural part of the caregiver's role, healthcare professionals must acknowledge that these culturally deep-rooted expectations had to be dissected to deliver manageable roles. The need for further study of the ethnic minority caregiver experience has implications for service development. The findings highlighted the need to examine caregiver experiences of caregiving in their duty by acknowledging the negative aspects of the role. Katbamna et al (2017) examined the role of balancing competing needs in the relationship between caregiving demand and caregiving outcomes (caregivers' role strain and depressive symptoms). Caregivers who did not balance competing needs were more likely to experience negative caregiving outcomes, suggesting that balance mediated between caregiving demand

and caregiving outcomes. The authors identified a mediator of negative caregiving effects that might help in developing tailored interventions for family caregivers of persons with dementia. A convenience sample of 120 family caregivers and care receivers with dementia were recruited to take part. Data were collected from family caregivers' self-completed questionnaires. A multiple regression analysis and evaluation of the significance of the indirect effect of caregiver balance were employed by the use of the Sobel test and Monte Carlo method, an alternative approach to testing mediation. Balancing competing needs completely mediated the association of caregiving demand with depressive symptoms and partially mediated the association of caregiving demand with role strain. The authors concluded that assessing caregivers' self-perceived sense of balance might help to identify caregivers at high risk for role strain and depressive symptoms. Thus, interventions to enhance caregivers' perceived sense of balance between competing needs may provide a strategy for reducing the negative effects of caregiving.

Acknowledgement to assessing burden, distress and cultural stresses to coping with caregiving could also extend the current study. The study had implications for service development, as the lack of personalisation and consideration of culture in current service provision was a major concern for the caregivers in this study influenced service use. The motivations and willingness to provide care should be considered by those professionals working to reduce caregiver distress.

7.7 PROGRAMME ACCESS AND BARRIERS TO UPTAKE

Within phase four of the study, a multi-disciplinary team of healthcare professionals put forward numerous suggestions regarding the uptake and lack of uptake concerning cardiac rehabilitation programmes. Unravelling the detail in categories highlighted physical activity to be a lifestyle factor that was considerably delayed to the recovery period with a 'continuation of sick role' being extended further than necessary by patients. Healthcare professionals emphasised the reluctance patients displayed when engaging in physical activity leading to a poor recovery outcome. However, within this, failure to recognise the family caregivers' role of restraint and worry made way for stereotypes to be emphasised without the detailed insight patients had to offer.

Healthcare professionals agreed that women's needs had to be addressed and understood to aid them in their recovery process of programme cardiac rehabilitation. Understanding and capturing knowledge of the Pakistani culture, ethnic background and language and communication barriers were imperative to build stronger relationships with the Pakistani population.

Healthcare professionals put forward suggestions of both visual and audio tools that would be culturally sensitive which pool together all the required information required to assist in the recovery of Pakistani patients and their family caregivers. It was hoped that visual resources would aid enhancement of unanswered questions. Tailored information specific to the needs of Pakistani patients was an essential part of the recovery programme of heart failure post discharge. This would form together a plan, which would assist and correlate the recovery of cardiac rehabilitation, enabling patients to feel empowered and consequently in turn adhering to recovery positively. Education needed to be delivered via cafés in the community led by HCPs. Healthcare professionals stressed the need for educational information and advice to be delivered within the community setting to both patients and family caregivers, where specific knowledge to concerns and worries could be addressed and, of course, encouraged access for all patients and family caregivers involved with caring for heart failure; thus, building and forming better relationships. This would create a platform of information, resources and knowledge. Health professionals would be at local community centres where cafés would take place to bring together professionals, patients and family caregivers within a hub environment to assist questions relating to cardiac rehabilitation. It was anticipated that the idea of community led cafés would help bridge the gaps outlined in the current study.

Healthcare professionals acknowledged the importance of treating patients as individuals whilst maintaining the role of cultural sensitivity. Interestingly, all members of the professional healthcare teams agreed and addressed ways in which service must be improved to accommodate the Pakistani population managing chronic heart failure.

It was agreed that a negotiated relationship, which would accommodate positive changes to both patient and family caregivers would be adopted. This would incorporate the essential requirement of addressing the needs of women, factoring in the Pakistani culture, ethnicity and language barriers. These factors would be important to building a better rapport, with improving the relationships between healthcare professionals and the knowledge of the Pakistani population, through the use of visual and audio tools that were tailored advice and educational resources. Such resources would need to be delivered via cafés in the community and be led by experienced culturally expert healthcare professionals.

Patients and family caregivers also expressed their views of the many barriers to uptake of cardiac rehabilitation. These included employment status, transportation difficulties, costs of travel, family caregivers stopping patients from attending cardiac rehabilitation programmes and the weather, in addition to symptomatic causes and lack of referral to programmes. The identification of these factors led to heart failure patients being unable to partake in cardiac rehabilitation programmes in the current study. Within wider literature amongst the South Asian population similarly, Chauhan et al (2010b) and Galdas & Kang (2010) identified a lack of time and transport barriers as reasons often cited by participants for not attending or completing cardiac rehabilitation. It was found that South Asian cardiovascular patients' cardiac rehabilitation needs in the UK (Tod et al, 2001a) similarly identified mobility, transport and distance to travel as structural barriers affecting attendance at a programme. Lack of referral was also a key barrier to enrolment and attendance at CR for the participants in this study (Tod et al, 2001b). This element was consistently identified as an enabling factor for enrolment in CR in the general population (Stiller & Holt, 2004; Beswick et al, 2005; Jackson et al, 2005) and in South Asian patients specifically (Banerjee et al, 2010; Grewal et al, 2010).

Further evidence of barriers to cardiac rehabilitation programme uptake were put forward by Tod et al (2001a) who collected data via telephone using a questionnaire informed by literature about South Asian patients' experiences of nursing care and found that many participants did not know, or were not told, of the cardiac rehabilitation provision that was available to them following discharge from the hospital. Some women also reported that they needed their husband's agreement to attend cardiac rehabilitation (Galdas et al, 2012). Banerjee et al (2007) reported that South Asian people were significantly less likely than 'white' patients to fully adhere to a six-month cardiac rehabilitation programme in Canada, despite having equal access and no cost barriers. Consistent with this finding, of the 25 patients (out of a total of 76 who had been told about the cardiac rehabilitation programme by health professionals in Tod et al's (2001b) study, only 16 reported that they had attended and only 6 had completed all of the sessions. Webster et al (2002) found that few participants recalled being visited by a cardiac rehabilitation nurse during their hospital stay and were particularly ill-informed about the cardiac rehabilitation programme, often confusing it with an exercise test or outpatient appointment. Of those who were aware of the programme only one half had attended the first session, the others did not attend because they were not sure what it entailed or were waiting to be formally invited (Galdas et al, 2012).

A large proportion of participants in Jolly et al's (2004) study did not have access to a car and were unable to attend an outpatient programme because of difficulty getting to the venue. Several participants expressed a preference for a private, home-based programme. However, a majority of participants preferred to attend hospital-based cardiac rehabilitation for reasons including motivation, feeling safer, being able to be monitored more closely by staff and the availability of equipment (Jolly et al, 2004).

These findings reflected the current study's results. Pakistani heart failure patients were much more motivated and felt secure within a setting where health professionals were present. Transport and location were particular barriers for many women in Visram et al's (2008) study, specifically, for women who were fearful of racial abuse when waiting outdoors for a taxi provided by the cardiac rehabilitation programme. Being in the presence of young male taxi drivers was considered particularly 'unacceptable' by some of the younger female cardiac rehabilitation attendees (Visram et al, 2008). Several participants also reported being anxious about attending cardiac rehabilitation sessions held in city locales that were associated with high crime rates (Visram et al, 2008). The timing of rehabilitation sessions was also problematic for some of the participants. Early afternoon or Friday CR workshops in particular conflicted with the call to prayer for Muslim women (Jummah). Most participants in Banerjee et al's study (2010a) reported attending CR in the evenings. Most had returned to work and were able to attend the CR programme because the site held evening classes (Galdas et al, 2012).

7.8 COMMUNICATION AND LANGUAGE

Language barriers and difficulties in accessing service provisions were challenges in this study that patients and family caregivers experienced. Family caregivers felt judged and stereotyped by health professionals leading them to believe that service provision was poorly administered as incorrect labelling of ethnic minorities led to the assumption that they were a passive community unable to modify lifestyle changes that would aid in self-care improvement. Family caregivers felt that their socio-economic status deterred health professionals from fully informing and supporting them which subsequently led to neglect.

Sources of support included care from family caregivers, information resources on-line, sources of faith and friendships. Having a support system in place encompassing the knowledge and understanding of the Pakistani culture and a network of service providers that comprehended the value of such resources, provided the care valued by the Pakistani community. Health service providers provided the functional and clinical support, but family members were perceived as members who would demonstrate ongoing care, thus requiring informed support for all members. Participants also made comments about the use of information pamphlets. Participants were disappointed with the reliance on pamphlets alone as opposed to human interaction with nurses that would provide explanatory schedules and information. Inadequate information was an issue that many family caregivers raised; it was a shortcoming that hindered care. It was evident that tailored information was pivotal in helping patients and their family caregivers thrive in optimal recovery.

Many patients who were eligible to attend a local cardiac rehabilitation education support group failed to do so as the inability to speak English was identified as a major reason to underpinning their decision not to enrol in the programme (Tod et al, 2001a).

Galdas et al's (2012) study findings showed that despite so few South Asian participants' inability to communicate fluently in English, none had received audio or video-taped rehabilitation information in their preferred language and only two patients remembered rehabilitation information being delivered by an interpreter. Other investigators concurred that not speaking English was a key barrier to South Asian patients' cardiac rehabilitation attendance and ability to access health information (Webster et al, 2002; Jolly et al, 2004; Astin et al, 2008; Chauhan et al, 2010b; Galdas & Kang, 2010). Webster et al (2002) and Galdas & Kang (2010) found that the implications of not being able to communicate verbally with healthcare professionals was frequently highlighted by their studies' participants and they seemed to appreciate the opportunity to discuss issues with the (studies' research assistants in their mother tongue.

Chauhan et al (2010b) reported that assumptions were made by health professionals based on participants' appearance and that negative experiences related to communication difficulties were recurring categories in their participants' interview narratives. In comparing a sample of ethnic minority cardiac rehabilitation attendees and non-attendee patients (the majority of whom were South Asian), Jolly et al (2004) showed that non-attendees were statistically significantly more likely to be non-English speaking and to have requested an interview in a minority language. Similarly, within the current study, Pakistani heart failure patients and their family caregivers felt judged and stereotyped depending on their geographical status and lack of education.

South Asian families in Astin et al's (2008) study found language barriers also meant that access to health information was frequently inadequate. It was reported that the patients' children were often required to interact with English speaking health professionals to provide their parents with cardiac rehabilitation advice. This lack of direct communication with South Asian patients provided health professionals with little opportunity to emphasise the importance of family involvement in the rehabilitation process (Astin et al, 2008), which was an issue that had been shown to play a key role in supporting and promoting CR attendance (Banerjee et al, 2010b; Chauhan et al, 2010a). Astin et al (2008) found that reliance on family members to communicate information generated other difficulties. Specifically, when children acted as interpreters, they and their non-English speaking parents reported feeling dissatisfied because of breaches in conventional family roles and expectations and privacy issues (Galdas et al, 2012). Furthermore, it was also reported that children tended to avoid conveying the negative aspects and seriousness of their parents' cardiac condition and, in a few cases, family members who acted as interpreters withheld information altogether to prevent the patient from becoming distressed or alarmed (Astin et al, 2008).

Despite a burgeoning of literature addressing patients' cardiac rehabilitation experiences and issues relating to poor uptake of, attendance at and adherence with, cardiac rehabilitation programmes (Beswick et al, 2004, 2005; Jackson et al, 2005) little empirical evidence was available to distil the cardiac rehabilitation experiences or patterns of attendance and adherence of individuals of South Asian origin (Galdas et al, 2012). This was surprising given the increased risk of coronary heart disease in this population and the significant benefit South Asian individuals stood to gain from cardiac rehabilitation programmes (Sahni & Leslie, 2005; Gupta et al, 2006). Galdas et al (2012) identified in several studies (Tod et al, 2001a; Webster et al, 2002; Jolly et al, 2004) that patients chose not to enrol, sporadically attended, or failed to complete a cardiac rehabilitation programme. However, only one empirical study (Banerjee et al, 2007) directly addressed issues of cardiac rehabilitation attendance and compliance amongst South Asian patients. Of particular concern was that this study reported South Asian patients were significantly less likely to complete a six month CR programme compared with other individuals (Banerjee et al, 2007).

7.9 PAKISTANI COMMUNITY

The emerging categories identified in the literature pointed towards several salient factors associated with South Asian patients' experiences of cardiac rehabilitation that commensurate with low uptake, adherence and effective cardiac rehabilitation. In particular, structural barriers relating to referral, timing, location and availability of transport were common, in addition to cultural and exercise-related barriers and language and translation difficulties (Tod et al, 2001a; Webster et al, 2002; Jolly et al, 2004; Visram et al, 2008; Chauhan et al, 2010a; Galdas & Kang, 2010). There was emerging evidence to suggest that South Asian women in particular appeared to experience socio-cultural barriers to attending, and participating in, conventional CR programmes (Astin et al, 2008; Visram et al, 2008; Chauhan et al, 2010a).

The present study found that Pakistani women specifically found it challenging and difficult to attend cardiac rehabilitation in a mixed-gender environment where male companions would hinder attendance. It was deemed to be culturally inappropriate and uncomfortable to perform physical activity in an environment that was of contention and taboo. Furthermore, clothing suited to the Pakistani community that would be culturally appropriate acted as a barrier to attending cardiac rehabilitation exercise classes. Heart failure patients felt that they must dress to suit the attire of the Pakistani heritage and Islamic faith. This would include covering fully when amongst a male environment; such exclusivity acted as a barrier to attending cardiac rehabilitation classes. Moreover, Pakistani women felt conscious of their expected roles and duties at home and amongst the community, thus unable to engage and participate in service provided cardiac rehabilitation.

Despite the identification of some distinct categories in the literature pertaining to specific cardiac rehabilitation needs for individuals of South Asian origin, overall, few researchers disaggregated their data by ethnic background to distil what might best meet the needs of South Asian patients or other sub-populations. Only one study (Kuppuswamy et al, 2004) examined a cardiac rehabilitation intervention, specifically designed for South Asian patients, although the authors did not describe the specific ‘culturally competent’ components of the programme. Nonetheless, the study findings were encouraging, suggesting that a cultural- and ethnic-specific cardiac rehabilitation intervention could improve South Asian patients’ attendance at cardiac rehabilitation and advance short-term outcomes and adherence to lifestyle changes (Galdas et al, 2012).

Identifying the lifestyle modifications, patterns of adherence and compliance and morbidity outcomes of patients attending culturally specific cardiac rehabilitation programmes compared with those who did not attend, or attend ‘generic’ CR programmes, would be key areas for future studies. Future research must recognise diversity in nationality, culture, language, lifestyle, socio-economic status, gender and religion (Gupta et al, 2006). Much of the existing literature has grouped and labelled participants as ‘South Asian’ (Tod et al, 2001a; Jolly et al, 2004; Banerjee et al, 2007; Banerjee et al, 2010; Astin et al, 2008) and, as a result, important cultural practices that could have a specific impact on CHD-related behaviour and risk management (Gupta et al, 2006) had been overlooked. Each community and specifically the Pakistani community required a tailored plan, which met the needs of this population in a culturally appropriate and sensitive manner.

It appeared that provision for patients with Pakistani backgrounds might be failing to meet their needs, which might affect compliance. To address these issues, informed culturally competent healthcare needed to be provided and the following points were worthy of consideration:

- Longer appointment times for service users where English was not their first language, and the recruitment of bilingual therapists. Written instructions, in English, with pictures should be provided.
- Understanding of the culture of their local community to enable them to incorporate the patient’s culture into their management; and

- Venues providing outreach within the community which would be of easy reach of the participant's vicinity.

Consistent with Aldred et al's (2005) study, a profound impact struck the lives of heart failure patients and their partners in the current study. Family caregivers indicated immense change in their everyday life and the impingement this had on their relationship with heart failure. However, contrary to Aldred et al (2005), family caregivers did recognise their caring role as burdensome. Mårtensson et al's (2001) study found the care giving experience to be positive when the spouse was given support and attention that encompassed informed information from health professionals. The experiences as highlighted in the current study showed that when the spouse was kept at a distance by the patient, they were socially isolated and received insufficient support, as experiences were negative.

The suggestion as put forward by healthcare professionals through focus group discussions of cafés and hub environments that encapsulated the target community whilst delivering healthcare promotion and education was one that must have its roots embedded in cultural sensitivity and awareness. It was recognised and agreed that community initiatives, emphasising the importance of health promotion were needed, most especially those with an understanding of cultural beliefs (Lawton et al, 2008). Netto et al (2010) described the term 'culturally sensitive' as often being used to describe interventions that adapted their approach for minority ethnic communities. The authors stressed that an understanding of strategies for adapting behavioural interventions for such communities was limited. Netto et al (2010) questioned in their research the main strategies for adapting interventions to reduce coronary heart disease (CHD) for minority ethnic communities and why such interventions had been adapted in these ways.

A systematic review investigated interventions for preventing CHD, including promoting physical activity, smoking cessation and healthier diets in Pakistani, Chinese and Indian communities in countries where these groups were minorities. Five principles for adapting behavioural interventions for minority ethnic communities were identified: (i) use community resources to publicise the intervention and increase accessibility; (ii) identify and address barriers to access and participation; (iii) develop communication strategies which are sensitive to language use and information requirements; (iv) work with cultural or religious values that either promote or hinder behavioural change; and (v) accommodate varying degrees of cultural identification representing significant progress in advancing understanding of adapted behavioural interventions for minority ethnic communities contributing to the field of targeted interventions for minority ethnic communities in five ways. Adapted behavioural interventions for preventing CHD amongst the communities in Europe and North America were rare. This indicated that many individuals in the Pakistani, Chinese and Indian communities might not be taking preventative action, and that urgent action was needed. It was found that South Asian communities were the major focus of research in the UK and Chinese communities in the USA. The review revealed considerable scope for adapting interventions to increase their appropriateness for the target communities by considering the multiple dimensions of individuals' lived experiences. These included their minority status, socially disadvantaged position, cultural and religious beliefs and cultural affiliation in addition to the five principles to guide the planning and delivery of future targeted interventions for minority ethnic communities. It was necessary to address deep-rooted influences on health-related behaviour to bring about change.

The final chapter will lead into a discussion of the key findings, contribution to knowledge, the studies strengths and limitations and future directions for research and researchers. The conclusions proposed draw upon my experiences of the research and the implications for practice grounded in existing, extant knowledge and new contribution.

8 CHAPTER EIGHT: CONTRIBUTION TO KNOWLEDGE, KEY FINDINGS, DIRECTIONS FOR FUTURE RESEARCH AND CONCLUSION

8.1 DEVELOPED THEORY, DISCUSSION OF A CONCEPTUAL FRAMEWORK, AND IMPLICATIONS FOR PRACTICE

Providing an explanation and prediction of linked concepts and relationships comprehensively was essential in developing a theory as it bound together and underpinned the crux of the phenomenon undertaken. There was a genuine need to address the core categories of uncertainty, struggle and poor understanding pertaining to language barriers, poor access to service provision and poor understanding of self-managing heart failure within the Pakistani community. These developing categories have led to an informed theory and explanation of the Pakistani heart failure patient needed which met the criteria of defining recommendations for a culturally appropriate tool.

The emergence of this theory added knowledge to the present study by promoting a concise understanding of heart failure within the Pakistani population. Understanding and addressing the needs of this population would in turn provide efficacy in service provision empowering and enhancing the level of knowledge and management between patients, family caregivers and healthcare professionals. It was deemed to be the responsibility of healthcare professionals working within the NHS services to work closely and collaboratively to deliver this appropriately in a culturally sensitive manner and consistently as demonstrated throughout this study. The present study added systematically a way of linking the findings, knowledge and understanding to the delivery of services and to the interface between target groups, Pakistani heart failure patients and their family caregivers and healthcare professionals.

It was imperative that initiatives were uniquely tailored to incorporate the cultural sensitivity as identified in this study in order to reap the benefits of long-lasting change. Earlier studies in line with the present study have addressed the persistent nature of cultural attitudes, community norms, socio-economic circumstances, and structural forces that acted as barriers to change in these ‘at risk’ communities. Examples of barriers identified through patient and family caregiver interviews and focus group discussions indicated how these might be used to inform health education programming and health policy-making at the individual, community and societal levels.

It was apparent that unless attention was focused on these factors, including deeply ingrained cultural beliefs, efforts to reduce heart failure disease and improve quality of self-management in ‘high risk’ groups were ill-fated. Furthermore, clear links needed to be established between such specific initiatives and wider heart disease frameworks to ensure transferability of learning and integration within wider service provision.

A framework, in which an effective service provision was implemented, was an important aspect for those living with heart failure as both patients and family caregivers, as it bridged the gaps of unmet needs. The point when patients required most knowledge and care must be delivered at each stage in order to meet the needs of patients to ensure efficacy of cardiac rehabilitation. A stage by stage process must uniquely and specifically target, equip and structure actions to ensure consistency in informed care giving. Carving out the truth to meet the realities of self-management and understanding heart failure was imperative to both patients and family caregivers. Its usefulness of theory in practice must remain fluid in consistency and productivity. A tailored manual that addressed the un-met needs, as emerged from current data, must incorporate ongoing cardiac rehabilitation care in the following stages:

- Admission
- Discharge
- On-going Management
- Family caregiver Management

Underpinning the foundations of effective cardiac rehabilitation was essential in-service delivery. The rapport of communication between patients, their family caregivers and health service providers has been better understood through this study as it has addressed the deficiencies and identified the driving needs that would address improvements. Understanding the cultural and ethnic values of the Pakistani population allowed health professionals to work closely with patients and their family caregivers to bridge the gaps of barriers including language, service provision and service delivery.

This study for the first time demonstrated that lifestyle risk factors and the self-management of heart failure within the Pakistani community both directly and indirectly had a significant impact in heart failure patients and their family caregivers who participated in this study. Thus, demonstration of commonalities and uniqueness provided a pathway for future research in areas that were neglected, underestimated, and generalised.

The present study strongly indicated the need for tailored educational health promotion programmes that were culturally sensitive. The adoption of such interventions, tailored specially for Pakistani heart failure patients and their family caregivers, could help to prevent the risk of heart failure, re-admissions to hospital and rapid declines in health status for those who were already affected.

The Pakistani population in this study was a unique component; they shared their experiences, which were influenced by religion and cultural beliefs. Health professionals subsequently should hone on information elicited from this study when devising guidelines for future health care provision. Health education and awareness raising discussions with the Pakistani communities were needed; promoting the benefits of healthy eating and cooking, managing medicines, stopping smoking and physical activity must be delivered in a culturally sensitive manner. These sessions must endeavour to influence the major modifiable risk factors affecting those at risk of heart failure and those at risk of developing recurrent cardiac episodes.

The Pakistani community regrettably were lacking accurate information regarding the ability to control chronic heart failure and related co-morbidities. The main culprit was poor literacy, most especially in first generation participants. The current provision of written literature if received prior to discharge from hospital proved largely infective as illustrated by participants throughout this study. The choices of audio and visual materials were options, such as, local Asian media in addition to workshops at local community centres and at places of worship. Health education sessions around healthy eating and lifestyle, run by bilingual workers of the same gender as the participants, were a unique selling point that was to be encouraged. In addition to giving health information, participants would be feeling the added comfort of utilising their language skills in a secure environment of the group, through discussion and role playing. The availability of culturally appropriate, single-sex, local, community-based infrastructures would remove many of the barriers people from the Pakistani community faced when considering accessing physical activity sessions. It would also give prospective participants the confidence to participate in what might be an unfamiliar activity without fear of embarrassment.

Participants in the present study emphasised emotional distress, worries, fears and unresolved concerns. These disconcerting issues needed to be addressed by providing emotional support and providing access to social, personal and life skills which would result in an increase in self-efficacy and self-empowerment. Within the present study, neither a psychologist nor counselling services were able to lend support for participants; it was a service that was unavailable to patients. The provision of support, self-awareness and increased knowledge would be of value to individuals desiring comfort and education enhancing in turn self-confidence, empowerment and control of their healthcare status.

General Practitioners played an active role amongst their patients' lives. Participants deemed GPs as their first port of call, entrusting them to sign-post them to out-sourced specialised care. Unfortunately, a GP was unable to take part in the study; however, one feature of risk-factor management, namely smoking cessation was a campaign that demanded awareness-raising amongst the Pakistani community. Culturally sensitive services needed to be promoted and delivered in a culturally and religious acceptable manner. Prospective bilingual smoking cessation counsellors needed to be identified and supported through training.

There was a demand for culturally appropriate, accessible community-based rehabilitation services to Pakistani heart failure patients post formal discharge from hospital after a cardiac episode. Such service delivery commanded re-directing standardised threads of care to cater for participants and their family providers that required appropriate language skills with specific training in religious, ethnic and cultural sensitivity. Services should also include provision for those people suffering from related co-morbidities. Future policymaking, large-scale research projects must have the involvement and consultation with Pakistani communities and their community leaders ensuring from the outset, the inclusion of the communities' views including staff that originated from Pakistani communities at the strategic planning stage of any service.

The present study has provided an overview of the research findings grounded in extant knowledge and within new contribution of the present study. A conceptual account of the Pakistani origin heart failure patient living with heart failure has been provided. Findings from the study in comparison with the available literature have supported salient categories such as physical activity, culture and religion, programme access and support structures, communication and language, dietary needs and medicines management which contribute towards effective cardiac rehabilitation. This has brought to the forefront crucial knowledge that should inform future health promotion interventions and strategies and should help to provide culturally sensitive care for this large, heterogeneous group.

This study has described the challenges patients and their family caregivers faced when accessing cardiac rehabilitation post-discharge to their heart failure diagnosis. These findings have advanced healthcare professionals' knowledge by providing understanding of participant perceptions across the Pakistani heart failure experience. The theory to emerge from the study has provided the potential for further research on a larger geographical basis with both patients and their family caregivers as it has lent insight to a variation of viewpoints, contributing optimism to the needs of Pakistani patients and family caregivers of heart failure. These concepts were recommended and discussed within three phases.

- Pre-discharge: future research should be directed towards investigating the potential for community heart failure nurses to contact patients prior to discharge from hospital.
- Discharge: patients perceived the doctor as the most important source of information when they wished to ask questions and learn more of their condition. Further research would need to investigate how heart failure nurses could make opportunities to engage in tangible and meaningful care interactions with patients and their family caregivers in the short time available for a scheduled discharge.
- Post-discharge: further research has been recommended to probe how patients cope with the heart failure experience. Such knowledge would help facilitate and support patients during their rehabilitation journey.

It is not uncommon for people with heart failure, especially those who experience severe symptoms, to seek information and recommendations from HCPs (Hjelm & Atwine, 2011). People with heart failure involved in the present study also sought information from a variety of people other than HCPs, namely: friends, acquaintances and family members. This result is congruent with a study conducted in India, where people with diabetes learned about their disease through a variety of sources such as books, media and friends (Mendenhall et al, 2016). When a diversity of sources are used, there is a high risk for people to be exposed to less reliable or unreliable recommendations. Recommendations from others may influence people’s decisions to stop, alter or to maintain their care management.

The current findings are also congruent with those of Herlitz et al (2016) and Ramsay Wan et al (2012) who found that people who trust their HCPs, feel empowered to ask questions and make informed decisions which in turn leads to effective management of their chronic illness (Herlitz et al, 2016; Ramsay Wan et al, 2012).

Respecting one’s cultural background should be acknowledged when HCPs liaise and interact with heart failure patients. The cultural context must be taken into account when working with Pakistani patients with heart failure. It is recommended that HCPs provide information to patients with heart failure in a culturally appropriate and sensitive manner. Identifying culturally influenced practices can assist HCPs to understand the rationale for patients with heart failure choosing disease management methods. This information will ensure that HCPs are able to provide appropriate health education and support patients heart failure management regimes. This finding reflects those of Quandt et al (2013) who claimed that what people learn influences their illness related beliefs and their capacity to manage their condition. Thus, to enhance monitoring and support of patients’ self-management practices, HCPs need to have close and regular interactions with patients with heart failure. Healthcare professionals must include the skills of close observation and detailed evaluation to ascertain how each individual with heart failure has arrived at their own current self-management approach, and how it is currently working for them (or not) exemplifying person centred care.

A tailored service would be essential to assist and support the management of heart failure as each individual patient has specific functional needs past the rigid standard roll-out of care. The current study revealed a need for educational resources and materials alike to be distributed at the point of discharge on how to self-manage. Patients stressed the importance of having information that guided them through the process of self-management in areas of recovery relating to their cardiac rehabilitation journey. It was hoped that this would bridge the gap of explaining what exactly heart failure was and its causes in addition to the recovery process.

In addition to the standard cardiac rehabilitation needs and relating occupational needs, the thread that tied together the deeper underpinning of patient care was woven by cultural, religious and ethnic threads that were specific to the Pakistani population and one that lent itself to specifically advancing the care needs of this group.

The current study reported several unexpected outcomes upon which participants extended unique needs from stages of discharge to rehabilitation. Further exploration was required into the concept of how this impeded the patient’s ability to recover and engage fully in their lives post- diagnosis and discharge. The purpose of the study was to explore patient and family caregiver experiences of heart failure experiences post-discharge; however, patients reflected on their entire experiences from pre-admission to recovery. Further elaboration is needed to generate in-depth information in order to understand experiences from beginning to completion.

Recommendations for policy and practice included acknowledgement of the patient and family caregiver needs beyond the medically idealised type. It was suggested that a move away from the rigid content and delivery style would promote a greater focus on the subjective experience of chronic illness and thus thoughtfully address Pakistani heart failure patients in a culturally sensitive manner, considering physical exercise, dietary needs, language and communication preferences, religious and cultural needs and programme access and structure to enhance the uptake and efficacy of cardiac rehabilitation.

Proposal of an effective educational tool:

- Community centre support groups where patient and family caregivers can mutually meet to discuss their concerns and share worries;
- MDT support cafés for patient and family caregivers;
- Mosque meeting rooms where communities existing to place of worship can meet to better inform themselves of cardiac rehabilitation;
- Patient and family caregiver cafés in community;
- Interpreters' support;
- Face-to-face clinics;
- A support directory café consisting of visual and audio tools.

It is anticipated that healthcare professionals would facilitate education to both patients and their family caregivers in both an appropriate and culturally sensitive manner, which grasps the perspective and unique needs of the Pakistani heart failure patients and their family caregivers. The above facilities would address issues of lifestyle self-management at convenient amenities allowing patients and family caregivers to openly discuss and exchange concerns and worries in a relaxed and supported environment maximising their understanding and knowledge. Healthcare professionals would have the opportunity to empower participants and equip them with the tools they required to feel confident and thus, the distinct tailored assessments would act as gateways to effective cardiac rehabilitation weaving the fabric of knowledge with a view of encompassing negotiated pathways that would assist in delivering lasting and improved developments.

It was clear that the heart failure experience represented a period of re-adjustment in which patients and their family caregivers would experience varying degrees of cognitive, emotional and physical challenges. The experiences as described in this study have offered insight for professional practice. Participant experiences provided new knowledge on the types of concerns, anxieties and challenges faced when discharged with heart failure. A psychosocial dynamic of professional care was an essential component of practice for heart failure patients and their family caregivers.

Patient and family caregiver understanding of chronic heart failure were essential to the cultivation of successful cardiac rehabilitation. Healthcare professionals must endeavour to create culturally sensitive environments in which patients and their families, who struggle with low confidence, language and communication difficulties, understand service provision correctly and would be able to access confidently their rights and entitlements through awareness and knowledge. Stringent training should be administered to all health professionals so that they would be able to meet communities and bridge gaps as outlined in the current research. It was clear that services needed to work effectively to ensure all patients had local access to a wide range of mainstream and specialist provision which could meet individual needs. It would be essential that health professional's work closely with local authorities to ensure Pakistani heart failure patients were not isolated from cardiac rehabilitation or any outreach support both pre-discharge and post-discharge, in the hope that the much wider discrepancy was narrowed.

The broken and incomplete communication between healthcare professionals must bridge this essential need for coerciveness. Family caregivers expressed a keen eagerness to adapt to positive lifestyle changes which would enforce care of a positive nature.

Moreover, further research with Pakistani origin family caregivers was essential as it would underpin the exploration of the specific needs this groups' demands, allowing insight into the enablers and, most importantly, the barriers obstructing the efficacy of effectively managing and caring for patients living with heart failure. Insight into the family caregivers' roles, duties and expectations would encourage the understanding of the complexity that was woven within religion, culture and ethnicity. This serving obligation and commitment would enhance the health professional's knowledge alleviating and untangling the family caregivers' complex occupation and decreasing anguishes and burden.

It would be essential that further research would delve into the caregiving perspective as it would address and bridge the disparities of the straining and burdensome role it played with the hope that in turn it aided family caregivers in feeling supported with their struggles in a culturally sensitive and holistic manner.

The concerns family caregivers largely faced stemmed from an array of mixed emotions ranging from anxiety, depression, guilt, lack of self-worth and emptiness. The female family caregiver was submerged with multiple roles and responsibilities including marriage, offspring, managing own illnesses and treatment, judgement from community and extended family members in addition to caring duties leaving minimal time for her own needs. Further understanding of these concerns would help support service delivery which was a recommendation that needed to be adopted in the hope that alleviation of pressure was sought, reducing the prevention of the overbearing burden, and empowering and equipping family caregivers with the confidence and courage to cope and manage chronic heart failure.

Community heart failure and heart failure nurses were ideally placed to lead the development, delivery and evaluation of cardiac rehabilitation programmes. The education, monitoring and coaching features of cardiac rehabilitation fitted well with the skills and philosophical orientations of nursing practice (Clarke, 2009). The emerging themes identified might help nurses to develop guidelines for the design and delivery of culturally competent and safe

Pakistani heart failure programmes. The barriers that were identified supported suggestions drawn from the wider cardiac rehabilitation literature that social characteristics, individual patient needs and preferences, referral and location of cardiac rehabilitation programmes were key to maximising participation (Thompson, 2009). Pakistani individuals must address issues relating to exercise, language and communication while religious and cultural needs and preferences and programme access and structure needed to be addressed in a culturally relevant and culturally sensitive manner to enhance the uptake and efficacy of cardiac rehabilitation.

Several UK based community health projects designed to improve CHD prevention and rehabilitation among South Asian individuals, such as the LIP STUDY (Lip et al, 2004), Project Dil in Leicester (Farooqi & Bhavsar, 2001), the BRUM study in Birmingham (Jolly et al, 2009) and the Khush Dil project in Edinburgh (Mathews et al, 2007), have offered encouraging directions for healthcare professionals in the design and delivery of culturally sensitive cardiac rehabilitation services (Galdas et al, 2012). These programmes have primarily focused on health professional education, screening and culturally appropriate health promotion activities to encourage lifestyle change and to reduce CHD risk, with some positive outcomes reported (Farooqi & Bhavsar, 2001; Mathews et al, 2007) where, in general, nursing and healthcare services have tended to maintain a Euro-centric approach to healthcare delivery and to cardiac rehabilitation in particular.

In trend with the literature, the present study added specific insight and value into the perspectives of the Pakistani heart failure patients’ and family caregivers’ journeys offering a distinctive and unique understanding to the needs exclusively experienced by this community. The illustrated journeys, experiences and perceptions as displayed throughout this thesis through a range of specific and pertinent categories have promoted an understanding of the types of culturally specific and sensitive needs the Pakistani population required. Thus, setting a unique pathway for addressing the needs of this minority community as opposed to the White population or South Asians as many variations exist, and so to not be lost in translation when addressing the needs of minority groups, tailored information could exclusively meet the needs of this group making progress with communities that needed it the most.

Exploring numerous aspects of the Pakistani population in relation to managing heart failure and the journey of self-management provided deeper insights into the lived experience of the cardiac rehabilitation recovery process of a Pakistani participant and their display of lifestyle behaviours that would benefit future research of both patients and family caregivers. This study offered insights into the fundamental aspects of the Pakistani culture that influenced several aspects related to heart failure. These findings offered avenues for health professionals to formulate and implement tailored health programmes that catered to the sensitivity of the traditional Pakistani population.

The key findings of this study suggested that cardiac rehabilitation programmes needed to be improved by providing individualised information to patients, especially about lifestyle management. This meant providing information that was relevant to each patient, in enough detail to meet their individual needs and in a format that each of them was comfortable with considering their culture, faith and ethnicity. Health professionals needed to recognise the sophistication of patients' assessments of their risk of experiencing further cardiac related events and the choices they made to reduce this risk. This meant moving away from the view that patients should be 'compliant' with lifestyle targets or medicines and the moral implications associated with this view. Patients needed to be given more information about their condition, taking away any uncertainties, poor understanding and concerns, which health professionals greatly failed to deliver.

The present study has brought new contribution to the area of heart failure management within the Pakistani population. An array of positive guidance and knowledge for efficacy in practice of service provision has been demonstrated. Exploring the numerous aspects of the Pakistani population in relation to heart failure and lifestyle management has given insights as to why Pakistani heart failure patients demonstrated lifestyle health behaviours. Family caregiver interviews and focus group discussions with healthcare professionals have added value to the present study and in turn have provided new knowledge offering exclusive perspectives that could be explored further in future research. The implications for practice therefore could adopt these new guidance pathways and weave them into services, improving provision for all parties concerned.

The researcher believes that many pathways and new leads have opened to researchers in the present study. This study has offered insights into the fundamental aspects of the Pakistani culture that influenced several aspects related to heart failure. The present findings offered avenues to health professionals to adjust their current frameworks and promote, formulate and implement tailored health prevention programs that cater to the sensitivity of ethnic values, faith and traditions of the Pakistani culture. Family caregiver interviews and focus group discussions with healthcare professionals have added value to the study and in turn provided new knowledge that has multiple exclusive dimensions and perspectives that could be explored further in new research. An understanding of the present study has given a platform to adopt positive changes with a view of providing effective provision to channel the Pakistani community effectively considering their cultural needs and ethnic and religious values. The implications for further research could only enhance this minority community considering the present findings.

Further research, which successfully underpins the needs of the Pakistani population, would be needed. The present study has provided much value and insight into heart failure lifestyle management inclusive of specific ideologies that govern these amongst the patient and family caregivers within the Pakistani community. This would allow the opportunity for further research to be carried out and for researchers within the field to build upon such foundations as founded in the present study. The present study has offered insights into the fundamental aspects of the Pakistani culture that influenced several aspects related to heart failure. There would be room for future work to dissect the present study and focus on specific aspects, which could in turn build upon existing theory and contribute new knowledge to the Pakistani population.

8.2 STRENGTHS & LIMITATIONS OF THE STUDY

8.2.1 STRENGTHS

The researcher wishes to highlight what she believes were some of the key strengths of the current study. This study had uncovered unique findings; several researchers and multiple studies have studied the South Asian population more generally and have encompassed this label to represent individual groups. None have specifically honed in on one population addressing their culture or needs. The current study added and built on previous work highlighting the need to address individual populations in a culturally sensitive manner as each group represented its unique pathway. A new direction emerged which was bespoke to the Pakistani community and invoked inspiration for future studies, innovating new approaches to working with specific populations and understanding new concepts. In addition, healthcare professionals were given a platform and foundation for a better understanding of weaving together ways to make progress professionally.

The finding of this qualitative study, through interviews and focus group discussion, offered a unique insight into the views of service users and NHS staff in relation to the cardiac management of heart failure in the Pakistani population. To the researcher’s knowledge, there had been no previous research to address the question of how best to organise the needs of the Pakistani population and their service provision. Obtaining the views of stakeholder groups was an important first step in developing services that were likely to be acceptable to both service users and providers.

A major strength of this study was the fact that the participants were of mixed educational and socio-economic backgrounds reflecting a cross section of the Pakistani population.

A further strength of this study lay in the fact that family caregivers of heart failure patients were interviewed separately from the patients. By following this strategy, a clearer view of family caregiver experiences was apparent. Moreover, the methodology employed was appropriate for the current research as it underpinned the lived experiences of heart failure from amongst the patients' and family caregivers' perspectives and uniquely understood and captured the recovery and self-management journey of managing chronic heart failure.

8.2.2 LIMITATIONS OF THE STUDY

Studies are not without certain shortcomings and the researcher believes that acknowledgement of the limitations addressed in this study could act as a guide for future research opportunities.

Recruitment of healthcare professionals and family caregivers was particularly challenging, and these would be discussed in turn. A cardiologist was unable to take part in a focus group discussion due to work commitments and work schedule. Furthermore, countless attempts were made to arrange an interview with a GP. A psychologist was unavailable too as this service was not one that was on offer to patients. Employers (health-professional staff) were offered counselling services via the occupational health department but patients and family caregivers did not have a service whereby they could be referred to for help and support tackling their depression and challenging management of heart failure. There was a great need for patients and their family caregivers to be able to have an outlet emotionally and the service was failing, as it was unable to accommodate this practice.

Furthermore, it was recognised that whilst healthcare professionals acknowledged the importance of their clients' needs, they tended to give the acceptable view or the view that was in line with espoused professional values and so their professed behaviour in the focus group discussions as part of this study might not reflect how they behaved in practice, reducing and limiting an optimal active approach within the development of patient cardiac rehabilitation (Dihle et al, 2006; Saks, 1995).

Moreover, it would have been an interesting dynamic to understand the perspective of a female Muslim chaplain. This is an area that would be of interest and exploration in future work.

The search strategy from the literature review was limited to the English language and to studies published after 1997, which meant that some relevant publications might have been overlooked. The two NHS trusts and three hospital sites within the West Midlands adopted in this study might represent a shortcoming geographically as location might not be representable of other cities in the United Kingdom.

The current study employed nine family caregivers. Although much valuable rich data was extracted, input from a larger number of participants would give a wider perspective of understanding; this is worth consideration for future work. Nonetheless, the use of qualitative methods had enabled one to obtain a better understanding of the reasons why service users and health professionals held certain preferences for care delivery.

8.2.3 CONCLUSION

In conclusion, this thesis has explored the perceptions and experiences that can enable healthcare professionals to tailor and facilitate the needs of Pakistani heart failure patients and their family caregivers. Awareness of the complexities involved in managing heart failure will assist healthcare professionals to engage with people living with heart failure. The central principle identified was that both patients and family caregivers needed to feel empowered in self-managing cardiac rehabilitation, eliminating traits of struggle, limited understanding and uncertainty. This was essential in bringing control to self-managing chronic heart failure. A few actions could be taken to establish this. A multi-disciplinary team of healthcare professionals must reach agreement and rigorously assess schedules that meet the needs of their clients collaboratively and consistently. This was the pinnacle to effective cardiac rehabilitation within the Pakistani community. It was apparent from the structures of data analysis that tensions existed between patients, family caregivers and healthcare professionals. The culture of existing structures within the healthcare delivery pathways needed to readapt and unravel its delivery and recognise the ability to meet family caregiver and patient needs. Lifestyle management must be compromised collectively by all parties as a way of going forward. A culturally sensitive responsive approach was required to bridge the unique and relevant gaps as uncovered throughout the present study with a view to addressing the needs of the Pakistani communities and their cardiac rehabilitation journey.

It has been anticipated post the successful completion of my PhD that I would continue to explore research associated with the Pakistani population. Furthermore, I would like to explore the role family caregivers' conduct and explore this aspect further. I would like to interview multiple family caregivers as it is a community of caregivers within the family that take care of the patient. I would like to home in on the role of women within the capacity of a family caregiver and better understand this with a view to assisting their needs more specifically. I would like to address issues such as communities, judgments and feelings of anxiety and inadequacy. I feel particularly inclined to this area because it is one that I resonate myself more closely with as I am also a Pakistani woman with first-hand experience of living with multiple chronic illnesses and living as a family caregiver. I would explore this on a wider geographical basis to incorporate a variety of views across the UK. Furthermore, I feel interviews with healthcare professionals especially those who were unattainable in the present study, such as a psychologist and a cardiologist, would add value to further work because capturing and collating their professional perspectives would add dimensions that would address participant concerns as voiced throughout this study.

9 CHAPTER 9

9.1 RESEARCHER COMMENTARY

I am a PhD research student with a keen interest in health sciences. I particularly thrive by working with minority ethnic communities and researching the needs of these groups. Prior to embarking upon my PhD, I undertook a BSc in Psychology and an MSc in Cognitive Neuro-Psychology. Post my studies, I was employed in research posts relating to healthcare (stroke and coronary heart disease). It was from my employment roles that I developed an interest in heart failure and in specific working with minority ethnic groups, thus embarking my journey upon the PhD. The experience of the present study has been intense. I have acquired vast knowledge and insight into the many avenues research entails. Carrying out research was a steep learning process; it required stamina, perseverance and patience. I found this to be especially true when engaged in obtaining ethical approval. I was astounded by the length and period this took, both the University and especially NHS ethics. The processes and various gateways one had to pass through were vast. Furthermore, the data collection process and experiencing the various gateways to accessing participants to the study and healthcare professionals were challenging. I struggled with interviews with family caregivers and participants; this journey resonated with my conscious emotionally with regards to the struggles and coping mechanisms family caregivers endured. To illustrate examples:

‘The family caregiver of NN was so grieved, I can’t imagine what it would be like to have an adolescent daughter, a first-born who has heart failure in addition to thalassemia and type 1 diabetes. The mother was trying so hard to be brave and was trying to ‘hold’ it together, so many emotions to battle with trying to accommodate her daughter, other children and partner whilst acknowledging herself last’. I interviewed both the patient and family caregiver over three phases of the study. I grew a connection from both the patient and the mother. I saw a range of emotions and grievances which fuelled different management strategies. I felt helpless; I empathised with both perspectives of the patient and family caregiver, I understood the difficulties the patient faced medically and the heartache the mother grieved holistically. As a parent myself, I empathised with the stress of managing multiple roles and accounting for herself the least, however, I struggled to ‘put myself in her shoes’ when trying to understand the difficult challenge of managing a very poorly child who ultimately had a bleak outlook medically.

‘Feeling judged and a failure by external community members for their role as a family caregiver was an unfair part of the interview to listen to. I wondered how it is even possible for ‘others’ to make someone who is juggling so much to be made to feel so inadequate. This concept, though relatable through my own experiences, was one that was very saddening. Unfortunately, the good work the family caregiver did went unrecognised. The focus of external member of the community was not to praise and support but to judge which consequently led to family caregivers feeling further deflated in their role.’

‘The anxiety and feelings of depression, concern and frustration were overwhelming. Service provision was failing family caregivers in that they felt invisible to the strain of their role. Poor support and loneliness amplified the strain family caregivers endured. In specific, feeling stereotyped, given medicines for depression rather than therapeutic support and lack of financial support to mention a few were ‘let downs’ that would help considerably if due understanding of family caregiver needs were understood and supported. I feel that this group were side-lined, perhaps due to a lack of cultural understanding and language barriers.

Patients struggled with knowing what exactly their prognosis was, they genuinely had no idea what heart failure was and what the future meant for them. Faith was a strong component of their struggle that acted as a huge comfort to remain grounded. This was partly due to a genuine gratitude towards healthcare professionals especially from the older generation for the medicines they received. Heart failure patients knew that the medicines they took were free of charge on the NHS and that they were first grade drugs and not second-rate medicines that would compromise their health. However, I found that with the younger generation, more questioning of the efficacy of service provision was demanded. This type of questioning was a positive movement as it commanded inclusion and efficacy towards the Pakistani population. The concerns that were raised relating to feeling stereotyped were interesting, it showed that socioeconomic status was becoming irrelevant to learning and that healthcare provision needed to incorporate amenities that were of convenience to the Pakistani population as opposed to ignorance and rejection to health promotion and adaptation.’

I feel I have grown as a researcher as I have become to be much more patient. I have grasped that the rate at which various variables unravel and subsequently come together would be at a pace that I would not always able to organise, prioritise or plan for, some things were out of my control. These processes had a life of their own just as life outside of academia; so much of ‘life’ happens that one cannot be planned nor prepared for. Nevertheless, I have experienced a pleasant process in my research journey of collecting data from participants and working alongside healthcare professionals, my supervision team and colleagues. Furthermore, the advantages and disadvantages of being an ‘insider’ have been both valuable and challenging. The contribution of bringing a wealth of my own experience as a family caregiver to chronic illnesses, a volunteer placement, researcher and Pakistani Muslim added value to the study. Interviews with heart failure patients and family caregivers supported my study in that I was able to understand many cultural, religious and ethnic practices pertinent to the present study. This has been an advantage. However, being an ‘insider’ was not without its challenges. I was conscious of participant behaviour altering as a result of being someone who was from the same ethnic group. I feared this might have led to the participants feeling too relaxed and not deeming the study professional assuming that explanations of certain behaviours are a ‘norm’ and that my presence was informal which in turn might have led to taking certain scenarios for granted and potentially allowing participants to not disclose information that might have been important.

As an outsider having no personal medical history of heart failure or related chronic disease, I was partially able to empathise how much distress was being experienced through personal experience of living with a loved one who resembled symptoms of my participants. However, I was not in the same ‘club’ as the patients who were going through their challenges; I was looking through a glasshouse. I never knew the true extent of what it meant to be living with heart failure both as a patient and family caregiver. Therefore, I was apprehensive of the richness of data emerging in my interviews. I was always conscious and anxious of this matter despite best efforts of an interview schedule guiding my study.

Nevertheless, my journey has been a great learning experience. The skill sets attained have embedded much value both personally and academically and I very much look forward to ascertaining these in forthcoming works.

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11 APPENDICES SECTION

11.1 PATIENT INFORMATION SHEET (1)

Birmingham City University

Patient Information Sheet

You and your partner are being invited to take part in a research study.

Before you decide it is important for you both to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you and your partner wish to take part.

Part 1

What is the purpose of the study?

The purpose of this study is four fold. First we aim to find out more about 1) peoples experiences (patient & partner) of managing their health 2) Factors that help and hinder this process 3) How people feel about the 'job' of managing their own health 4) How people manage their lifestyle and heart medications.

Once we know more about these things we will use this information in part 2 to recommend a educational informational resource that will help health professionals and patients to work together to develop individualised action plans to support people managing their health after diagnosis of heart failure.

Why have I/We been chosen?

All Pakistani individuals and their partners diagnosed with heart failure are being invited to participate. It is estimated that 20 or more patients (and partners) will be invited to participate in this study.

Do I/We have to take part?

No. It is up to you and your partner to decide whether ***one, or both of you***, wishes to take part. If your partner does not want to take part, but you do, that is fine. You will be given this information sheet to keep and if you/your partner wish to take part you be asked individually to sign a consent form. You are (both) still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you/your partner receives.

What will happen to me/us if I/we take part?

If you decide to participate in the research you/your partner will be asked to take part in two interviews at your home which will last approximately 30-60 minutes each and be audio-taped (phase 1). 2 interviews will take place for the patient. These will occur before and after your cardiac rehabilitation programme after your discharge from hospital. 1 interview will be carried out with the carer.

In phase 2 earlier findings will be used to recommend a self management ‘tool’. A team of health care professionals will be invited to take part in a focus group consisting of Cardiologist, Cardiac Nursing Team, Dietician, Physiotherapist, Psychologist, GP, Pharmacist and Spiritual-Pastor (Imam). The perspectives of the barriers and facilitators that the service delivers to patients and carers will be further explore and the views of these professionals will be included in order to accumulate appropriate recommendations for a tool can be made explicit and designed for this population.

Once you/both have signed the consent form(s) your address and telephone number will be passed onto a researcher and you will be contacted to arrange a convenient time at which you can be visited at home for the first interview. You will be given a copy of the consent form to keep and a second copy will be filed in your medical records. If at any time you become distressed during the interviews you can be given details about the Heart Care Cardiac Support Group who offer a help-line service. If this is necessary the researcher will let your GP know that she has recommended this approach.

Would my/our taking part in this study be kept confidential?

All information collected about you and your partner during the course of the research will be strictly confidential. Any information about either of you will have your name and address removed so that you cannot be identified from it. The interview tapes will be labelled with a number (not a name) to ensure that you cannot be identified. All electronic data will be password protected and anonymised. For patients consenting to take part in the research your medical records (the patient only) may be inspected by a researcher to record the nature of your coronary disease and any relevant past medical history that you might have. The questionnaires that you complete will be anonymous and all data (tapes and questionnaires) will be stored in a separate and secure location and destroyed 24 months after the end of the study.

What would happen to the findings of the research?

Researchers will examine the discussions arising from the interviews and look for repeated themes, ideas and experiences. Once analysis of all interviews has been completed you will be sent a summary of these for information and comment. It is hoped that findings will be published approximately 12-months later, but you will not be identified in any report or publication. If for any reason during the study, you or your partner should lose the capacity to consent you would be withdrawn from the study. Data already collected up to that point would be used.

What are the possible benefits of taking part?

Although there are no direct clinical benefits associated with taking part in this study, some people find it beneficial to discuss their feeling and experiences after being in hospital. The findings from this study will be used to help us recommend an educational information resource that patients and health professionals can use together to make individualised action plans to support self management after discharge from hospital with diagnosed heart failure.

Would the reader be able to identify individuals?

No. All of the information will be presented in an anonymous form. Any reports or publications relating to the study will be completely anonymous too.

Who has reviewed the study?

The study has been approved by West Midlands - Solihull Research Ethics Committee and Birmingham City University Sponsorship Committee.

Sources of support available

A Patient Advice Liaison Service (PALS) will be made available for you to access should you wish to seek advice, any further information and support in resolving concerns you may have. PALS is a friendly, accessible and confidential service which aims to use patient experiences and/or comments to influence service change and development towards making a positive difference in the delivery of healthcare locally.

The PALS team at City hospital is:

Nayna Patel – Patient Support Centre Lead

Stevie Woodhouse – Patient Support Centre Assistant

Norma Bayliss- Patient Support Centre Assistant

Opening times: 9.00am – 4.30pm

Consultation by appointment: 10.00am – 3.00pm

Telephone: 0121 507 5836

Email: swb-tr.pals@nhs.net

The PALS team at Russell's Hall is:

Manager Karen Jaunzems (karen.jaunzems@dgoh.nhs.uk)

PALS Officer Denise Yates (denise.yates@dgoh.nhs.uk)

Patient Information and PALS Support Officer Anita Foster (anita.foster@dgoh.nhs.uk).

Tel: 0800 073 0510

The PALS team at Wolverhampton Royal Hospital is:

The PALS team can be contacted on 01902 695362

Mobile number: 07880 601085. Email address is pals@rwh-tr.nhs.uk.

Patient Information Centre opening hours - 9am and 5pm Monday to Friday.

Travel expenses

Travel expenses will be reimbursed in addition to a lunch voucher for you should you wish to be interviewed at a site other than your home.

Contact for further information:

I am very happy to discuss any issues or questions you might have before making any decision or if for any reason you agree to take part and then change your mind, you may withdraw from the study by leaving a message. Please contact me, or one of the team members, on 0121 2024539. Thank you for reading this.

Miss Rifat Yusuf (PhD Research Student)

Birmingham City University.

11.2 PATIENT INFORMATION SHEET (2)

Birmingham City University

Participant Information Sheet

You and your partner are being invited to take part in a research study.

Before you decide it is important for you both to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you and your partner wish to take part.

Part 1

What is the purpose of the study?

The purpose of this study is four fold. First we aim to find out more about 1) peoples experiences (patient & partner) of managing their health 2) Factors that help and hinder this process 3) How people feel about the ‘job’ of managing their own health 4) How people manage their lifestyle and heart medications.

Once we know more about these things we will use this information in part 2 to recommend a educational informational resource that will help health professionals and patients to work together to develop individualised action plans to support people managing their health after diagnosis of heart failure.

Why have I/We been chosen?

All Pakistani individuals and their partners diagnosed with heart failure are being invited to participate. It is estimated that 20 or more patients (and partners) will be invited to participate in this study.

Do I/We have to take part?

No. It is up to you and your partner to decide whether ***one***, ***or both of you***, wishes to take part. If your partner does not want to take part, but you do, that is fine. You will be given this information sheet to keep and if you/your partner wish to take part you be asked individually to sign a consent form. You are (both) still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you/your partner receives.

What will happen to me/us if I/we take part?

If you decide to participate in the research you/your partner will be asked to take part in two interviews at your home which will last approximately 30-60 minutes each and be audio-taped (phase 1). 2 interviews will take place for the patient. These will occur before and after your cardiac rehabilitation programme after your discharge from hospital. 1 interview will be carried out with the carer.

In phase 2 earlier findings will be used to recommend a self management ‘tool’. A team of health care professionals will be invited to take part in a focus group consisting of Cardiologist, Cardiac Nursing Team, Dietician, Physiotherapist, Psychologist, GP, Pharmacist and Spiritual-Pastor (Imam). The perspectives of the barriers and facilitators that the service delivers to patients and carers will be further explore and the views of these professionals will be included in order to accumulate appropriate recommendations for a tool can be made explicit and designed for this population.

Once you/both have signed the consent form(s) your address and telephone number will be passed onto a researcher and you will be contacted to arrange a convenient time at which you can be visited at home for the first interview. You will be given a copy of the consent form to keep and a second copy will be filed in your medical records. If at any time you become distressed during the interviews you can be given details about the Heart Care Cardiac Support Group who offer a help-line service. If this is necessary the researcher will let your GP know that she has recommended this approach.

Would my/our taking part in this study be kept confidential?

All information collected about you and your partner during the course of the research will be strictly confidential. Any information about either of you will have your name and address removed so that you cannot be identified from it. The interview tapes will be labelled with a number (not a name) to ensure that you cannot be identified. All electronic data will be password protected and anonymised. For patients consenting to take part in the research your medical records (the patient only) may be inspected by a researcher to record the nature of your coronary disease and any relevant past medical history that you might have. The questionnaires that you complete will be anonymous and all data (tapes and questionnaires) will be stored in a separate and secure location, and destroyed 24 months after the end of the study.

What would happen to the findings of the research?

Researchers will examine the discussions arising from the interviews and look for repeated themes, ideas and experiences. Once analysis of all interviews has been completed you will be sent a summary of these for information and comment. It is hoped that findings will be published approximately 12-months later, but you will not be identified in any report or publication. If for any reason during the study, you or your partner should lose the capacity to consent you would be withdrawn from the study. Data already collected up to that point would be used.

What are the possible benefits of taking part?

Although there are no direct clinical benefits associated with taking part in this study, some people find it beneficial to discuss their feeling and experiences after being in hospital. The findings from this study will be used to help us recommend an educational information resource that patients and health professionals can use together to make individualised action plans to support self management after discharge from hospital with diagnosed heart failure.

Would the reader be able to identify individuals?

No. All of the information will be presented in an anonymous form. Any reports or publications relating to the study will be completely anonymous too.

Who has reviewed the study?

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Sources of support available

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Tel: 0800 073 0510

The PALS team at Wolverhampton Royal Hospital is:

The PALS team can be contacted on 01902 695362

Mobile number: 07880 601085. Email address is pals@rwh-tr.nhs.uk.

Patient Information Centre opening hours - 9am and 5pm Monday to Friday.

Travel expenses

Travel expenses will be reimbursed in addition to a lunch voucher for you should you wish to be interviewed at a site other than your home.

Contact for further information:

I am very happy to discuss any issues or questions you might have before making any decision or if for any reason you agree to take part and then change your mind, you may withdraw from the study by leaving a message. Please contact me, or one of the team members, on 0121 2024539. Thank you for reading this.

Miss Rifat Yusuf (PhD Research Student)

Birmingham City University.

11.3 CARER INFORMATION SHEET (1)

Birmingham City University

Carer Information Sheet

You and your partner are being invited to take part in a research study.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you and your partner wish to take part.

Part 1

What is the purpose of the study?

The purpose of this study is four fold. First we aim to find out more about 1) peoples experiences (patient & partner) of managing their health 2) Factors that help and hinder this process 3) How people feel about the ‘job’ of managing their own health 4) How people manage their lifestyle and heart medications.

Once we know more about these things we will use this information in part 2 to recommend a educational informational resource that will help health professionals and patients to work together to develop individualised action plans to support people managing their health after diagnosis of heart failure.

Why have I/We been chosen?

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Do I/We have to take part?

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What will happen to me/us if I/we take part?

If you decide to participate in the research you will be asked to take part one interview at your home which will last approximately 30-60 minutes each and be audio-taped. 2 interviews will be carried out with your partner. A team of health care professionals will be invited to take part in a focus group consisting of Cardiologist, Cardiac Nursing Team, Dietician, Physiotherapist, Psychologist, GP, Pharmacist and Spiritual-Pastor (Imam). The perspectives of the barriers and facilitators that the service delivers to patients and carers will be further explore and the views of these professionals will be included in order to accumulate appropriate recommendations for an educational resource can be made explicit and designed for this population.

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What would happen to the findings of the research?

Researchers will examine the discussions arising from the interviews and look for repeated themes, ideas and experiences. Once analysis of all interviews has been completed you will be sent a summary of these for information and comment. It is hoped that findings will be published approximately 12-months later, but you will not be identified in any report or publication. If for any reason during the study, you or your partner should lose the capacity to consent you would be withdrawn from the study. Data already collected up to that point would be used.

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Consultation by appointment: 10.00am – 3.00pm

Telephone: 0121 507 5836

Email: swb-tr.pals@nhs.net

The PALS team at Russell's Hall is:

Manager Karen Jaunzems (karen.jaunzems@dgoh.nhs.uk)

PALS Officer Denise Yates (denise.yates@dgoh.nhs.uk)

Patient Information and PALS Support Officer Anita Foster (anita.foster@dgoh.nhs.uk).

Tel: 0800 073 0510

The PALS team at Wolverhampton Royal Hospital is:

The PALS team can be contacted on 01902 695362

Mobile number: 07880 601085. Email address is pals@rwh-tr.nhs.uk.

Patient Information Centre opening hours - 9am and 5pm Monday to Friday.

Travel expenses

Travel expenses will be reimbursed in addition to a lunch voucher for you should you wish to be interviewed at a site other than your home.

Contact for further information:

I am very happy to discuss any issues or questions you might have before making any decision or if for any reason you agree to take part and then change your mind, you may withdraw from the study by leaving a message. Please contact me, or one of the team members, on 0121 2024539. Thank you for reading this.

Miss Rifat Yusuf (PhD Research Student)

Birmingham City University.

11.4 CARER INFORMATION SHEET (2)

Birmingham City University

Carer Information Sheet

You and your partner are being invited to take part in a research study.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen to you if you take part
- Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you and your partner wish to take part.

Part 1

What is the purpose of the study?

The purpose of this study is four fold. First we aim to find out more about 1) peoples experiences (patient & partner) of managing their health 2) Factors that help and hinder this process 3) How people feel about the 'job' of managing their own health 4) How people manage their lifestyle and heart medications.

Once we know more about these things we will use this information in part 2 to recommend a educational informational resource that will help health professionals and patients to work together to develop individualised action plans to support people managing their health after diagnosis of heart failure.

Why have I/We been chosen?

All Pakistani individuals and their partners diagnosed with heart failure are being invited to participate. It is estimated that 20 or more patients (and partners) will be invited to participate in this study.

Do I/We have to take part?

No. It is up to you and your partner to decide whether ***one***, ***or both of you***, wishes to take part. If your partner does not want to take part, but you do, that is fine. You will be given this information sheet to keep and if you/your partner wish to take part you be asked individually to sign a consent form. You are (both) still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you/your partner receives.

What will happen to me/us if I/we take part?

If you decide to participate in the research you will be asked to take part one interview at your home which will last approximately 30-60 minutes each and be audio-taped. 2 interviews will be carried out with your partner. A team of health care professionals will be invited to take part in a focus group consisting of Cardiologist, Cardiac Nursing Team, Dietician, Physiotherapist, Psychologist, GP, Pharmacist and Spiritual-Pastor (Imam). The perspectives of the barriers and facilitators that the service delivers to patients and carers will be further explore and the views of these professionals will be included in order to accumulate appropriate recommendations for an educational resource can be made explicit and designed for this population.

Once you have signed the consent form(s) your address and telephone number will be passed onto a researcher and you will be contacted to arrange a convenient time at which you can be visited at home for the first interview. You will be given a copy of the consent form to keep and a second copy will be filed in your medical records. If at any time you become distressed during the interviews you can be given details about the Heart Care Cardiac Support Group who offer a help-line service. If this is necessary the researcher will let your GP know that she has recommended this approach.

Would my/our taking part in this study be kept confidential?

All information collected about you and your partner during the course of the research will be strictly confidential. Any information about either of you will have your name and address removed so that you cannot be identified from it. The interview tapes will be labelled with a number (not a name) to ensure that you cannot be identified. All electronic data will be password protected and anonymised. For patients consenting to take part in the research your medical records (the patient only) may be inspected by a researcher to record the nature of your coronary disease and any relevant past medical history that you might have. The questionnaires that you complete will be anonymous and all data (tapes and questionnaires) will be stored in a separate and secure location, and destroyed 24 months after the end of the study.

What would happen to the findings of the research?

Researchers will examine the discussions arising from the interviews and look for repeated themes, ideas and experiences. Once analysis of all interviews has been completed you will be sent a summary of these for information and comment. It is hoped that findings will be published approximately 12-months later, but you will not be identified in any report or publication. If for any reason during the study, you or your partner should lose the capacity to consent you would be withdrawn from the study. Data already collected up to that point would be used.

What are the possible benefits of taking part?

Although there are no direct clinical benefits associated with taking part in this study, some people find it beneficial to discuss their feeling and experiences after being in hospital. The findings from this study will be used to help us recommend an educational information resource that patients and health professionals can use together to make individualised action plans to support self management after discharge from hospital with diagnosed heart failure.

Would the reader be able to identify individuals?

No. All of the information will be presented in an anonymous form. Any reports or publications relating to the study will be completely anonymous too.

Who has reviewed the study?

The study has been approved by West Midlands - Solihull Research Ethics Committee and Birmingham City University Sponsorship Committee.

Sources of support available

A Patient Advice Liaison Service (PALS) will be made available for you to access should you wish to seek advice, any further information and support in resolving concerns you may have. PALS is a friendly, accessible and confidential service which aims to use patient experiences and/or comments to influence service change and development towards making a positive difference in the delivery of healthcare locally.

The PALS team at City hospital is:

Nayna Patel – Patient Support Centre Lead

Stevie Woodhouse – Patient Support Centre Assistant

Norma Bayliss- Patient Support Centre Assistant

Opening times: 9.00am – 4.30pm

Consultation by appointment: 10.00am – 3.00pm

Telephone: 0121 507 5836

Email: swb-tr.pals@nhs.net

The PALS team at Russell’s Hall is:

Manager Karen Jaunzems (karen.jaunzems@dgoh.nhs.uk)

PALS Officer Denise Yates (denise.yates@dgoh.nhs.uk)

Patient Information and PALS Support Officer Anita Foster (anita.foster@dgoh.nhs.uk).

Tel: 0800 073 0510

The PALS team at Wolverhampton Royal Hospital is:

The PALS team can be contacted on 01902 695362

Mobile number: 07880 601085. Email address is pals@rwh-tr.nhs.uk.

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Contact for further information:

I am very happy to discuss any issues or questions you might have before making any decision or if for any reason you agree to take part and then change your mind, you may withdraw from the study by leaving a message. Please contact me, or one of the team members, on 0121 2024539. Thank you for reading this.

Miss Rifat Yusuf (PhD Research Student)

Birmingham City University.

11.5 PARTICIPANT LETTER OF INVITATION

Birmingham City University

PARTICIPANT LETTER OF INVITATION (WITH REPLY SLIP)

Dear Mr/Mrs _____________,

We are writing to you to invite you to participate in a study called;

'A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study'

The project is being conducted by a team from Birmingham City University. We aim to:

1. Understand more about how you care for your health, especially your lifestyle and prescribed medications, after your discharge from hospital;
2. Understand the experiences and needs of male and female Pakistani HF patients and their carers following discharge from hospital in order to identify barriers and facilitators to management and access to rehabilitation services.

3. Using this information we aim to propose a ‘tool’ which will help patients and health professionals to work together in managing health after discharge from hospital with heart failure

Participation in this study is entirely optional and will in no way effect your treatment. For your information, this study does not involve any hospital visits, medication regimens or physically uncomfortable procedures. The study has 2 parts.

1) We would like to invite you to participate. If you decided to take part a researcher would visit you at home on 2 occasions to discuss the above topics. There are no right or wrong answers to these questions; we are interested in your point of view.

2) We will use the information from 1) to propose recommendations for a ‘tool’ to help people to manage their condition more effectively.

If you live alone, or with your partner and are interested in this study, you will find enclosed an information sheet which explains the study in more detail. Please read the attached information sheet. If you think that you might be interested in taking part in the study, please email or phone us to confirm your participation, and to arrange an interview with one of the team.

I would like to thank you for taking the time to read this information sheet.

If you have any other queries regarding the study please feel free to contact Rifat Yusuf on 0121 202 4539 or rifat.yusuf@bcu.ac.uk

Regards

Reply Slip

I Mr/Mrs _____________, would like to be contacted to discuss the possibility of my taking part in

the research study described in this letter called -

‘A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study’

I can be contacted on (please supply two contact numbers if possible)

Contact number 1) _____________,

Contact number 2) _____________,

If desired please specify your preference for a contact time (am or pm) please.

Please return your slip using the SAE attached.

11.6 HEALTHCARE PROFESSIONAL INFORMATION SHEET

Birmingham City University

Dear Sir/Madam,

I am writing to you to invite you to participate in a study called;

‘A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study’

The project is being conducted by a team from Birmingham City University.

The aim of my study is to carry out a focus group discussion with a health care professional team consisting of a:

- Cardiologist
- Cardiac Nursing Team
- Dietician
- GP
- Physiotherapist
- Psychologist
- Pharmacist
- Spiritual-Pastor (Imam)

to identify potential tool development.

The aim is to gather the perspectives of a multi-disciplinary team to identify the barriers and facilitators that the service delivers to patients and carers with a view to make some appropriate recommendations for a tool can be designed for the Pakistani heart failure population.

All information obtained from the focus group will be kept confidential and it is anticipated that the focus group will last approximately 1-2 hours. The focus group will take place at Birmingham City hospital.

Thanks you for the time you have taken to read this letter. If you have any other queries regarding the study please feel free to contact Rifat Yusuf on 0121 202 4539

Regards

Reply Slip

I Mr/Mrs _____________, would like to be contacted to discuss the possibility of my taking part in the research study described in this letter called -

‘A Cross Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study’

I can be contacted on (please supply two contact numbers if possible)

Contact number 1) _____________,

Contact number 2) _____________,

Please return your slip using the SAE attached.

11.7 PATIENT AND PUBLIC CONSULTATION

Friday 4th March 2012

Birmingham City Hospital

3 volunteer service users

I sat with them individually to run through the topic guide questions that would be administered to the patients.

1 male, 71yr's, volunteer since 5 years

1 female, 68yr's, volunteer since 11 months

1 female, 73 yr's, volunteer since 15 years

The service users tended to talk about their own experiences and answered questions relating to the topic guide, though this was not the purpose, it made it clear that the questions were being understood. The service users all collectively felt the questions were appropriate and not offensive in any manner.

A point to consider was that not all patients are confident to talk about their experiences and are quite withdrawn, feel scared and have little knowledge of a real understanding of their condition from their experiences of volunteering so be gentle and conscious that not all patients will open up to talking as different personalities exist and not all patients accept their condition so they may be in denial and not very forthcoming about discussing their experiences and self-management.

1 carer

1 female carer, 59 yrs

All questions were appropriate and didn’t feel uncomfortable with answering any of the questions. A point of consideration was marked in that just to be conscious that during interview carer may become upset as the role of caring can be difficult at times and distressing.

11.8 VOLUNTEER PLACEMENT LOG

Phase 1 – diagnosis and hospital admission

Phase 2 – consultant meeting (identify rehabilitation needs)

Phase 3 – rehabilitation (community/hospital based)

Phase 4 – extended rehabilitation (home/clinic based)

A two year, two fold volunteer placement was undertaken at Sandwell and West Birmingham Hospitals NHS Trust. A criminal records bureau (CRB) disclosure was cleared in April 2011 enabling me to contribute voluntarily to patients and their carers with their cardiac care at the cardiac rehabilitation unit. I underwent training appropriate to volunteering over the course of 3 days where administrative training relating to staff ID badges, role of volunteer, uniform and trust policies and procedure of a volunteer was undertaken. My main duties were:

- Listening to patients and their carers and befriending them
- Assisting staff with their duties in caring for patients and their carers
- Running appropriate basic errands for staff
- Welcoming patients and their carers
- Helping with clerical duties
- Complying with trust policies and procedures
- Displaying a helpful and friendly courteous attitude
- Monitor the number of patients helped through their sessions
- Observe confidentiality and deal with patients and visitors in a friendly and non-discriminatory manner
- Recognise patient anxieties, thus requiring calmness and understanding
- Understanding health and safety issues relating to the area based in and working within
- Communicating clearly with staff, patients and visitors
- Showing willingness to help and work as part of a team
- Attend meetings and open days/fun days and departmental events
- Undergo a CRB check
- Assist with exercise programme training under supervision of staff member

I volunteered on a Monday evening for 12 months at mixed class where both men and women who were employed and as result working during the day attended an exercise rehabilitation class in the evenings. Post this placement I volunteered on a Friday morning for another 12 months at a ladies only class. The cardiac unit saw over five hundred patients per week displaying an array of cardiac conditions. My role involved working alongside the cardiac nurses in assessing the patients to monitoring them throughout their class session. Patients were of all ethnicities ranging from South Asian to White and African Caribbean.

The mixed class where many working professionals attended was a very active and social atmosphere where cardiac patients worked hard to achieve and maintain their fitness levels. Patients were keen to be holistically managed. For example, patients wanted to be weighed, talk about their lifestyle and risk factors and medicines and continue with their exercise sessions allowing them a holistic plan of care. I did meet patients that were depressed due to a loss of role in not being able to work and therefore relying on partners to fulfil financial support which led to a specific patient to feel depressed and rely upon alcohol. This particular patient lacked emotional support and therefore I would find myself talking to him on many occasions supporting him to adhere to attending class and his exercise programme.

The ladies only class was small in numbers but interesting. A few ladies past their phase four level continued to attend whereas those put forward for the class to attend only the duration prescribed were unfortunately unable to continue as a majority of their partners who attended with them didn’t want them to continue exercise class though they really enjoyed the social aspect of it and physical aspect. Women who attended often had carers attend with them who would wait for them either in the car park or in a waiting room. Barriers such as language often made communicating difficult with staff, I very often found myself translating and talking to ladies who were unable to communicate their concerns. Dress code of the women tended to be traditional wear accompanied by trainers; this was deemed acceptable by family and staff. Often, some women brought along with them female carers who would sit in the gym whilst they trained as male gym instructors were present. The staff members were very accommodating and helpful towards these ladies. Initial assessments of blood pressure and weight were carried out upon arrival, if needed a sugar insulin diabetes blood test to assess whether patient was fit to exercise and not at risk. Following this a tailored plan for patients was followed where my role would be to assist the patients and accompany them in making sure they adhered to it. The women only session were very empowering to patients as it gave the ladies confidence to look after their health. It was upsetting to see some women due to family commitments leave at the end of their programme when it wasn’t their choice to do so but a family members sadly.

I engaged into my role very swiftly and thoroughly enjoyed my time volunteering. The insight into patients and carers concerns and demands allowed me the insight into cardiac conditions and the various types of barriers and enablers they faced building a platform of knowledge that would help as part of my study. My confidence was built as I was able to build a rapport with staff and patients and understand procedures, practice and terminologies. In addition, I learnt of the types of issues patients faced. For example, language, co-morbidities alongside heart disease, cultural issues that needed more sensitivity such as dress code and being accompanied by family member, lack of confidence in being able to be vocal about things that would bother patients such as wanting to continue but unable to due to family commitments and expectations. I would help patients seek advice if they wished to take part in Ramadan through professional staff that would advise them of medication management and diet management also.

All these factors equipped me to understand the types of issues I may encounter with data collection and the sensitivity that would be required to assist patients and their carers. My relationship with health care professionals was a really positive experience; the staff members were encouraging of my interests and supportive with any information that would help my knowledge and aid development.

11.9 TOPIC GUIDES: PATIENT/CAREGIVER

Birmingham City University

TOPIC GUIDE

Introduction

- Introduce self
- Confirm research aims before interview
- Take ID.
- Remind of importance of their role, confidentiality (no individualised information is fed back to NHS/GP).
- Establish if spouse/partner wishes to participate, if so complete consent forms.
- Explain structure/duration of interview.
- Gain consent to use tape recorder.
- Establish ground rules; no right or wrong answers.
- Is there anything you want to ask or discuss before we start our interview?
- Record demographic and biological details.
- Explain that there is no right or wrong answer. We are interested in their experience. Try and minimize background noise if possible. One person speaking at a time. Aim to see carer alone if agreeable.
- Switch tape/Digital DSS recorder on.
- Thank participant at the end of the interview and reassure them about confidentiality of information regarding their interview.

PATIENT - Interview 1

Understanding CHF

Could you tell me what happened when you found out about your CHF condition?

Probe

- What were you told?
- What happened in hospital?
- How did you feel once you were discharged from hospital?
- How did you find out?
- What do you understand about CHF?

Many people have ideas about what caused their heart condition? Can you tell me what you think caused yours?

Probe

- How did you decide that these factors were important?
- Do you know how these factors affect your heart?
- How do you feel about your condition?

The next few questions are about things that you do may do in your day-to-day life to stay healthy. Is there anything specific you do to stay healthy?

Probe

- Why did you choose these specific activities?
- What information sources (nurse, Dr, GP, internet, friend, relative)
- How might these activities benefit you?

Can you tell me more about your experience of making healthy lifestyle changes?

Probe

- Have you experienced any difficulties?
- Do you have ideas as what you should doing e.g. targets/goals
- Is there anything that helps you to achieve these?
- Is there anyone who helps you achieve these?
- Is there anything that hinders you from achieving these?
- Is there anyone that hinders you from achieving these?
- What would make it easier to manage your lifestyle changes?

Self Management

How do you think you have been managing your health since you were discharged from hospital?

Is there anyone that helps you with the things you need to do to look after the health of your heart at the moment?

Is there anything that could help you that you don't have?

Are there any obstacles that you face that make it difficult for you to look after the health of your heart at the moment?

How do you tackle and overcome any challenges, what support networks do you have or access?

Moving on to ask you a little about yourself and how CHF has affected you, can you tell me a little bit more about the day-to-day processes and how it has been for you?

Is there anything that we have not discussed that should be considered when helping people to care for them after discharge of CHF?

Medication

Thinking about your medicines, what medicines are you taking?

Probe

- What helps you with managing your medication?
- What do you understand about your medications?
- How do you feel your medications help you?
- Do you have any concerns regarding your medicines?
- How do you feel about the medication you take?

Diet

Since your diagnosis, have you made changes to your diet in order to try and keep healthy?

Probe

- What are these?
- If you smoke, how do you think smoking affects your health?

Exercise

How do you feel about attending cardiac rehabilitation?

What are your thoughts about the exercises you have been taught there?

Prior to your diagnosis, what exercise did you do before?

What do you feel are the benefits of exercise?

Do any of your family members of friends and relatives help you with exercise?

Faith

How important does your faith play a part in the management of your condition?

PATIENT - Interview 2

Lifestyle

How would you describe your health at the moment?

Probe

- Explore Issue of maintenance
- Sources of support
- Difficulties or challenges experienced
- Barriers and enablers

Physical/Emotional/Psychological Responses

How you feel physically?

Probe

- Looking back, how do you think this experience has affected you (mood, relationships etc)
- Support from friends/ family/ professionals
- Do you experience any pain and symptoms related to your condition?
- How do you manage your symptoms and condition?

Recovery

Probe

- How do you feel you've progressed and adjusted since you came out of hospital?
- Are there any parts of your recovery that you have found challenging?
- If yes, what were the challenges that you faced and how did you manage them?

Understanding of illness

What are your views of your heart illness?

Probe

- Can you tell me a little bit more about why you have this view and what sources of information helped you to develop this view?
- What do you feel is the cause of your condition?
- Do you think there is anything that you can do to positively affect the health of your heart as time goes on?
- Which of these do you think is the most beneficial to your health and how do you think it benefits your heart?

Lifestyle changes

I would like to move on now and talk with you in more detail about some of the lifestyle changes that you have made.

Physical activity

What was your experience of cardiac rehabilitation?

Probe

- Do you think it helped your recovery?
- Did you feel that the programme was suitable for your needs?
- Do you think that improvements could be made to the programme?
- Have you maintained any of the exercises out of class?
- What was your experience of CR women only class/mix class?
- Which do you prefer and why?
- How do you feel that staff at CR interacted with you?
- Is there anything you wanted help with a CR and didn't receive?

Smoking (if applicable)

Smoking is a very difficult habit to break and something that is not easy, could you start by telling me where you are with your smoking at the moment?

Probe

- Most people find it difficult to reduce or stay off cigarettes. Can you tell me about your experiences?

Diet

If it's ok with you, I would like to know about how you feel about your diet now?

Probe

- Do you feel there has been a change to the way you think about food?
- Has your weight changed since your rehabilitation programme?
- How do you manage your diet around family and events? For example – Eid, Birthdays, Ramadan etc

Medication Management

Next I would like to ask you to think about the medications you take in relation to your CHF and how you have been managing them.

What has been your experience of taking your medications?

Sources of Support

I would like to finish by asking you about sources of support. Can you tell me what and/or who have been your greatest sources of support?

Probe

- Is there anything else that we could provide to support you during your recovery?
- Is there anything else you would like to add about your experience of HF and the rehab programme?

CARER PHASE 3

Adjustment

Since your partner's diagnosis, can you tell me about how adjusting has been for you during this time?

If you think about when you partner was first discharged and returned home after hospital compared to now, do you think anything has changed?

Do you feel cardiac rehabilitation has helped with your partners condition and how they feel about themselves, for example their outlook?

How has your partner condition affected and changed your life?

What activities do you share together?

Life changes

Can you tell me about any change that you and your partner have made in your day-to-day life to improve your heart health?

Probes:

- Are there any changes that you think are more important than others?
- Do you and your partner generally agree on which changes are important?
- Do you feel that you and your partner have been successful with making changes?
- Do you feel that you and your partner share the responsibility for making changes?
- What's the strain of living with a CHF patient – has it been difficult for you, if so could you describe how?
- Do you worry about you partners condition?
- Do you have any concerns or worries?
- Do you feel you know and understand your partner's diagnosis?
- Do you feel that you are being supported?

Diet

Can you tell me how do you and your partner organise your meals?

Probes:

- How do you decide what to eat?
- How do you manage the shopping and choose food items for your meals?
- How do you preparing and serve your meals?
- Has the way you organise your meals changed since your partner had their CHF?
- Have you done anything that you think has helped your partner to change his/her eating habits?
- Was there anything or anyone that made this it difficult for you?
- Was there anything or anyone that helped you?
- Did making changes in eating ever cause tension between you and your partner?

Exercise/Physical activity

Can you tell me about any changes in exercise/physical activity habits that you and your partner have made since the procedure?

Probes:

- Have you done anything that you think has helped your partner to change his/her exercise/physical activity levels?
- Was there anything or anyone that made this it difficult for you?
- Was there anything or anyone that helped you?
- Have you any experience of going to cardiac rehabilitation classes?
- Did making changes in exercise/physical activity levels ever cause tension between you and your partner?
- Do you feel CR has been effective to attend for your partner?

Medications

Can you tell me about anything you have done to help your partner manage his/her medications?

Probes:

- Was there anything that made it difficult for you to support your partner with managing medications?
- Was there anything that helped you to support your partner with managing medications?
- Did issues around medications ever cause tension between you and your partner?

Cigarette smoking

Can you tell me how your partner is doing with managing his/her cigarette smoking?

Probes:

- Have you played a part in helping them manage their cigarette smoking?
- Was there anything that made it difficult for you to support your partner with managing cigarette smoking?
- Was there anything that helped you to support your partner with managing cigarette smoking?
- Did issues around cigarette smoking ever cause tension between you and your partner?

Self

Can you tell me how you feel that your partner’s heart condition has affected you?

Probe:

- How has it affected your role as a partner?
- How has it affected your family?
- Do you have any particular worries or concerns?
- Is there anything or anyone who has supported you through this time?
- Was there anything that would have helped you that you did not get?
- Employment

Concluding

Is there anything you would like to add?

Probe:

- Are there any improvements that could be made to the care you/partner have had?
- Was there anything aspect of your care that was especially good?

PATIENT - PHASE 1

- Post-discharge, how has your recovery been? – coming home, rehab, adapting, routine, self, family, relations
- What was your expectations of CR?- travel, other members, staff, gym clothes,
- What were your feelings about CR programme?- worried, scared, excited, nervous, beneficial,
- Risk factors management – diet, exercise, medications, BP, self/stress, alcohol, co-morbidity’s, smoking

MEDICATION:

- Do you take your medication regularly?
- What helps you with managing medication?
- Why do you take medication?

- Do you find it difficult to take medications?
- Do you forget to take your medications?
- What do you take?
- How long have you been taking?
- Do you understand why you’re taking your medications and their side effects?
- What do you understand about your medications?
- How do you manage your medications?
- Do you take them regularly?
- Do you miss your medications?
- Do you feel they help you?

DIET:

1. Diet (salt, breakfast, lunch, dinner, snacks, family events, social, religious)
2. Do you drink alcohol?
3. Do you smoke, if so how much daily? Have you cut down? How do you think smoking affects your health? Do you think smoking is harming your health?

EXERCISE:

1. How much activity do you do on a daily basis?
2. You have heart failure, how much exercise do you think you should do?
3. Do you think you exercise enough?
4. What are the barriers and facilitators to exercising?
5. Do any of your family members of friends and relatives help you with exercise?
6. Do your family encourage you to be active?
7. Physical activity (chores, walks, activity, rehabilitation class)
8. What do you expect CR will be like? Are you excited, nervous, worried?
9. What do you understand about CR?
10. CR – how do you feel about CHF?
11. How do you manage your health condition?
12. How does it make you feel?
13. What help could you want/need?
14. Do you feel CR is important?

SELF-MANAGEMENT

The next few questions are about things that you do in your day-to-day life that may affect your health. I would like to focus specifically on things that you do that you think will affect the health of your heart.

- At the moment is there anything that you do, or intend to do, that you think is important to keep your heart healthy on a day-to-day basis?

(Probe: Tell me a little bit more about how do you achieve this? Do you set yourself a target/goal?)

1. Can you tell me what you do to keep your heart healthy? How did you come to choose these particular changes to make?

(Aim: Explore rationale behind their choice of self-management activity i.e. Why did they choose this particular activity? Who or what encouraged them. What information source did they use?)

2. How well do you think you have been managing the health of heart at the moment and how do you know?

(Aim: Explore how confident they feel about their self-management activities and whether they monitor/evaluate their success/progress).

3. Is there anything you do which you think might be unhealthy for your heart?

(Aim: Explore lifestyle habits that the participant considers unhealthy)

The next few questions are about things, people situations that help you or hinder you in looking after the health of your heart.

4. Is there anyone that helps you with the things you need to do to look after the health of your heart at the moment?

(Aim: Explore sources of support e.g. family member, community member, health professional, other)

5. In what way have they helped you?

(Aim: Explore the nature of support they have. Is it 'instrumental' i.e. assistance with activities of daily living or 'emotional' i.e. caring, understanding and empathy)

6. Can you think of anything that helps you to manage the health of your heart at the moment?

(Probes: Do you have any special skills that help you? Do you use any ‘tools’ to help you? Are there any situations that you find difficult? Any useful tips, strategies, practical points that might help others? Is there anything that could help you that you don’t have?).

(Aim: To explore any factors that help participants to self-manage their condition in their daily life.)

7. Are there any obstacles that you face that make it difficult for you to look after the health of your heart at the moment?

(Aim: Explore barriers to self-management. These may be personal (emotional reactions/uncertainty/physical constraints/co-morbidities/financial constraints/ family commitments etc), organisational (Access to services, healthcare, awareness of available services e.g. cardiac rehabilitation, conflicting advice).

8. Moving on to ask you a little about yourself and how CHF has affected you, can you tell me a little bit more about the journey and how it has been for you? How has CHF made you feel?
    - Coping with life on daily basis - conscious of condition, adapting, moving around, carrying out chores
    - Support/relationships/family/friends
    - Anxiety, mood, fears, stress regarding self
    - Co-morbidities
    - Employment
    - How do you feel managing your condition?
    - Do these symptoms prevent you from daily tasks?
    - What do you think causes your symptoms?
    - What do you do to manage your symptoms?
    - What is your outlook in life?
    - Has any part of you social life changed?
    - Has your role changed since the procedure?

In the last part of our discussion we would like to ask you about how you manage your prescribed medications.

9. How are you managing with taking your heart medications at the moment?

(Aim: To explore whether they are having any difficulties e.g. lack of knowledge, side effects, difficulty with remembering, stigma of taking medications etc)

10. Is there anything that helps you with taking these medications currently?
11. Is there anything that makes taking the medications difficult at the moment?
12. In the last few minutes, do you have any other comments in relation to what we have discussed?
13. Is there anything that we have not discussed that we should take into consideration when helping people to care for themselves after discharge of CHF?

Understanding CHF

1. Can you tell me about how you found out you had a problem with your heart?

Probe What happened?

How did you find out?

Any other problems in the past

What would you do if you should develop symptoms again?

What do you understand about CHF?

2. Lots of people have ideas about what caused their heart condition? Can you tell me what you think caused yours?

Probe How did you decide that these factors were important?

Do you know how these factors affect your heart?

What does you CHF mean to you? How do you feel about your condition?

3. The next few questions are about things that you do may do in your day-to-day life to stay healthy. Is there anything specific you do to stay healthy?

Probe Why did you choose these specific activities?

What information sources (nurse, Dr, GP, internet, friend, relative)

How might these activities benefit you?

Do you do anything that is unhealthy?

4. Can you tell me more about your experience of making healthy lifestyle changes?

Probe Have you experienced any difficulties?

Do you have a clear idea of what you should doing e.g. targets/goals

Do you know how to achieve these targets/goals?

Is there anything that helps you to achieve these? (Why/how/specific)

Is there anyone who helps you achieve these? (Who/how)

Is there anything that hinders you from achieving these? (Why/how)

Is there anyone that hinders you from achieving these? (Who/how)

What would make it easier to manage your lifestyle changes?

5. In the last part of our discussion we would like to ask you about how you manage your prescribed medications*.*

Probe Have you experienced any difficulties?

Do you understand why you are taking each of your medications?

What would make it easier for you to manage your medications?

Could you tell me about how you found out you had a problem with your heart?

Recap - have I covered: symptoms, did they affect their life, beliefs about cause, symptoms since, what would they do to manage them, quality of the information that you have received how to manage any symptoms

2. Lots of people have ideas about what caused their heart illness. Can you tell me what you think caused yours?

Recap - have I covered: how they think each of these factors affected their heart?

3. The next few questions are about things that you do in your day-to-day life that may affect your health. I would like to focus specifically on things that you do that you think will affect the health of your heart. - (activities good and bad)

At the moment is there anything that you do, or intend to do, that you think is important to keep your heart healthy on a day-to-day basis?

Recap - have I covered: how they came to choose these particular changes to make? How well they think they have been managing the health of heart - anything unhealthy?

4. The next few questions are about things, people situations that help you or hinder you in looking after the health of your heart. Is there anyone that helps you with the things you need to do to look after the health of your heart at the moment?

Recap - have I covered: how helped, what, what obstacles?

5. In the last part of our discussion we would like to ask you about how you manage your prescribed medications.

Recap - have I covered: How are they managing, anything that helps/ makes taking the medications difficult at the moment

Faith

  - Fatalistic beliefs
  - Attitudes
  - Prayer
  - Meditation

PATIENT PHASE 2 –

- Post-discharge, how has your recovery been? – coming home, rehab, adapting, routine, self, family, relations
- What was your experience of CR?- travel, other members, staff, gym clothes,

- What were your feelings about CR programme?- worried, scared, excited, nervous, beneficial,
- Risk factors management – diet, exercise, medications, BP, self/stress, alcohol, co-morbidity’s, smoking

1. Lifestyle

    - How would you describe your health at the moment compared to before the procedure? *(patient’s journey)*

    - Lifestyle changes: goals, expectations and experiences compared to previous interview. Explore Issue of maintenance. Have they been able to maintain the behaviours they instigated or had intentions to do in phase 1

    - Getting back to normal/ back to employment - expectations v reality

    - Sources of support and messages / context regarding lifestyle to make these changes - personal vs professional - and support preferences (*cardiac rehab? - other contact from diary)*. Difficulties/challenges they have experienced/Barriers and enablers.

Hint - trying to get at what they are willing to give up, able to give up, intend to give up. And how these choices are made, concepts of agency and responsibility, collaboration continuum. Coherence between changes and their understanding of risk factors, symptom and cause attribution, perception of their candidacy).

2) Pain

- Have they experienced any sensations/aches/feelings in relation to their problems with their heart
    - i. How would you describe it
    - ii. What effect does this have on you
    - iii. How do you feel about it

    iv. When and how often does it come on
    v. How do you manage it (contact professional)

2. Emotional/ psychological responses

    - Looking back - how do you think this experience has affected you (mood, relationships etc)

    - Develop on concept of support from friends/ family/ professionals and the preferences for these

Hint - develop more of a picture of their journey, beyond the physical manifestations, range of sometimes mismatched responses to their experience, what the process may have triggered.

A: Intro & Symptom Management & Beliefs About Cause

Could you tell me about how you found out you had a problem with your heart?

- Can you describe the symptoms that you got related to your heart condition before diagnosed CHF?
- Can you describe what they were like?
- Did these symptoms affect your life in any way?
- What do you think caused you to have such symptoms?
- Have you had any symptoms since your discharge?
- If you were to develop symptoms can you tell me what you would do to manage them?
- Can you tell me about the quality of the information that you have received how to manage any symptoms?

Aim: Explore: What symptoms mean in the context of patients understanding of their CHD. How do patients make sense of symptoms and manage them?

2. Lots of people have ideas about what caused their heart illness. Can you tell me what you think caused yours?

- You mentioned a couple of factors that you thought might have caused your heart disease. Can you explain to me how you think each of these factors affect your heart?

Aim: What are patients' beliefs about the cause of their own CHD? How do they relate to their own Profile?

General question about recovery

1. How do you feel you've progressed and adjusted since you came out of hospital?

Probes:

- Are there any parts of your recovery that you have found challenging?

- If yes, what were the challenges that you faced and how did you manage them?

- We are hoping to improve the support that people receive whilst recovering from angioplasty. Can you suggest anything that we could offer that would have made your recovery easier?

Understanding of illness

2. Lots of people have different ideas about their illness and I would like to ask you a bit more about your views of your heart illness.

Probes:

- Can you tell me a little bit more about why you have this view and what sources of information helped you to develop this view?

- Do you think there is anything that you can do to positively affect the health of your heart as time goes on? (yes/no)

(If yes and mentions several factors continue with…)

- You have mentioned several things that you can do which might have a positive affect on your heart health. Which of these do you think is the most beneficial to your health and how do you think it benefits your heart?

Lifestyle changes (refer to earlier interviews to establish what individual changes have been made to inform which of the questions to include)

3. I would like to move on now and talk with you in more detail about some of the lifestyle changes that you have made.

- How did you decide which lifestyle changes you were going to make and what influenced your decision?

3a) Physical activity

- Looking back on the last week, how many times have you done some physical activity where you have got out of breath/puff?

Post-cardiac rehabilitation – risk factors – adapting, barriers, facilitators, post-management, exercise programme, experience of getting there, staff, problems and difficulties, what part was enjoyed, disliked, staff, how do you feel for CHF and CR, has knowledge of CHF and CR and SM improved?

- Can you tell me about what type of physical activity you were doing and for roughly how many minutes please (10 minutes or more)

Probes:

- When did you first decide to increase your level of physical activity?

- What motivated you to make this change in your lifestyle?
- Once you decided to make changes in your levels of physical exercise. How did you decide what form of exercise to do and for how long at each session?

- Is there anything or anyone that has helped or hindered you in making regular physical activity a part of your life (the barriers and success to adhering these changes)

- Some people find it difficult to be consistent with their levels of physical exercise from week to week. How would you describe your experience?

- We have found that some people felt that they did not get enough information about physical activity levels to do, whereas others did. What was your experience?

3b) Smoking (if applicable)

We all know that smoking is a very difficult habit to break and something that is not easy. Could you start by telling me where you are with your smoking at the moment?

Probes:

- When did you first decide to quit or cut down (A lot of success with smoking, why this change of lifestyle focus?)

- Why did you decide to quit/cut down?
- Is there anything that has helped you with cutting down or quitting smoking?

- Is there anything that has been a barrier to you successfully cutting down/quitting smoking?

- Most people find it difficult to reduce or stay off cigarettes. Can you tell me about your experiences?

3c) Diet

If it’s ok with you, I would like you to think about the different types of foods that you have eaten in the last week.

- On average how many servings of fruit and or vegetables would you have managed to eat per day?

- How many portions of red meat in the last week?

- How many portions of oily fish in the last week?

- How many portions of fried food meals in the last week?

-Since the procedure, do you think your weight has changed? (If yes)

- What do you think has contributed to this weight change?

- Do you either cook with salt or add it to your meals?

- Are you conscious of adding extra salt, oil and sugary in-take?

- Do you eat a lot of traditional foods?

- How do you manage your diet around family and events? For example – Eid, Birthdays, Ramadan etc ..

4. Medication Management

Next I would like to ask you to think about the medications you take in relation to your CHF and how you have been managing them.

- Have there been any changes with you medications over the last 6 months? Have any been stopped or started or ceased temporarily?

-Have you experienced any problems with taking your medications?

-How do you feel your medications benefit you?

-Some people experience side effects from taking their medication. What has your experience been of this?

-Some people take medications on a short term basis and some for a lifetime. Can you tell me about which group your medications would fall into? In other words are any of them to be taken for short term only and any for lifetime?

5. Sources of Support

I would like to finish by asking you about sources of support. The early months can be challenging, and people may turn to others or use their own ways of managing their recovery. Can you tell me what and/or who have been your greatest sources of support over the last 6 months?

- Is there anything else that we could provide to support you during your recovery?

- Is there anything else you would like to add?

11.10 TOPIC GUIDES: CARER

TOPIC GUIDE

Title of study:

A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study

Aim(s) of the investigation:

The aim of the study is to explore the experiences and needs of male and female Pakistani HF patients and their carers following discharge from hospital in order to provide insights into barriers and facilitators to management and access to rehabilitation services.

Objectives:

- To explore the experiences, attitudes and knowledge of Pakistani HF patients and carers following discharge from hospital with a view to understanding their lifestyle management and adaptation
- Investigate expectations of the cardiac rehabilitation process including associated risk factors
- Explore the needs of a Pakistani population to understand the impact of gender and cultural backgrounds with a view to understanding barriers and facilitators and improving care and needs on the experiences of HF
- Develop a resource to improve access of Coronary Heart Disease rehabilitation services for patients
- Propose a tool to improve provision of culturally and linguistically appropriate service and delivery

Interview & Focus Group Schedule

- Cardiac Rehabilitation Phase2 - T1 Interview with patient & carer (understanding & knowledge of HF, expectations of rehabilitation, perceptions of disease, barriers & facilitators to attending and adhering) Interview 1 will be at patient and carer home and will explore understanding and knowledge of HF, risk factors, management of condition on a daily basis (Aim 1/2)

- Cardiac Rehabilitation Phase3 - T2 Interview with patient & carer (adaptation, experiences, attitudes, risk factors, barriers & facilitators, self-management) Interview 2 post a 12-week gap of rehabilitation attendance will explore problems faced during rehabilitation (physical rehabilitation/psychological). An understanding of the process for both men and women will be addressed here to assess the journey, experiences and barriers faced with a view to disseminating information as to what patient and carer needs are (Aim 3)

- Focus Group – 1 with HCP's (Multi-Disciplinary Team) consisting of Cardiologist, Cardiac Nursing Team, Dietician, Physiotherapist, Psychologist, Pharmacist and Spiritual-Pastoral Caregivers to identify potential tool development (Aim 4). The aim of the focus group is to carry out a discussion with a multiple team of healthcare professionals in order to perspectives of the barriers and facilitators that the service delivers to patients and carers so that appropriate recommendations for a tool can be made explicit and designed for this population.

1 PATIENT INTERVIEW SCHEDULE PRE-CARDIAC REHABILITATION - (understanding & knowledge of CHF, expectations of rehabilitation, perceptions of disease, barriers & facilitators to attending and adhering)

2 PATIENT INTERVIEW SCHEDULE POST-CARDIAC REHABILTATION - (adaptation, experiences, attitudes, risk factors, barriers & facilitators, self-management) Interview 2 post a 12-week gap of rehabilitation attendance will explore problems faced during rehabilitation (physical rehabilitation/psychological). An understanding of the process for both men and women will be addressed here to assess the journey, experiences and barriers faced with a view to disseminating information as to what patient and carer needs are

1A CARER INTERVIEW SCHEDULE PRE-CARDIAC REHABILITATION (1-QUESTION (open) 2-PROBE (bullet points) 3-AIM (over - arching)

2A CARER INTERVIEW SCHEDULE POST-CARDIAC REHABILITATION

HCP INTERVIEW SCHEDULE - (The aim of the focus group is to carry out a discussion with a multiple team of healthcare professionals in order to learn of their perspectives of the barriers and facilitators of the service delivered)

- Cardiologist

    - Cardiac Nursing Team
    - Dietician, Physiotherapist
    - Psychologist
    - Pharmacist
    - Spiritual-Pastor

Introduction

- Introduce self
- Provide information about research aims and take ID.
- Remind of importance of their role, confidentiality (no individualised information is fed back to NHS/GP).
- Establish if spouse/partner wishes to participate, if so complete consent forms.
- Explain structure/duration of interview.
- Gain consent to use tape recorder.
- Establish ground rules; no right or wrong answers.
- Record demographic and biological details.
- Say questions verbatim to get continuity, even if repetitive.
- Explain that there is no right or wrong answer. We are interested in their experience. Try and minimize background noise if possible. One person speaking at a time. Aim to see carer alone if agreeable.
- Switch tape/Digital DSS recorder on.
- Thank participant at the end of the interview and reassure them about confidentiality of information regarding their interview.

CARER -

Opening Questions

1 - Since your partner’s diagnosis, can you tell me about how it has been for you during this time?

2 - If you think about the first few weeks of your partner’s return home compared to now, do you think anything has changed?

2 - Do you feel cardiac rehabilitation has helped with your partners condition and how they feel about themselves, for example their outlook?

2 - How has your partner condition affected and changed your life?

2 - What activities do you share together?

Making ‘Life’ Changes

2 - Can you tell me about any change that you and your partner have made in your day-to-day life to improve your heart health?

Probes:

- Are there any changes that you think are more important than others?
- Do you and your partner generally agree on which changes are important?
- How did you decide which changes to make?
- Do you feel that you and your partner have been successful with making changes?
- Do you feel that you and your partner share the responsibility for making changes?
- How has your motivation been to keep up these changes?
- Mental/emotional stress, what’s the strain of living with a CHF patient – has it been difficult for you, if so could you describe how?
- Relationship impact, has it been difficult post procedure, has it changed if so how?
- Do you worry about you partners condition?
- Do you have any concerns or worries?
- Do you feel you know and understand your partner’s diagnosis?
- How do you cope with your partner’s adjustment, mood, anxiety, do you find this difficult?
- Do you feel that you are being supported?
- Does your partner acknowledge the strain of your role? Are you supported?

Diet

2 - Can you tell me how do you and your partner organise your meals?

Probes:

- How do you decide what to eat?
- How do you manage the shopping and choose food items for your meals?
- How do you preparing and serve your meals?
- Has the way you organise your meals changed since your partner had their CHF?
- Have you done anything that you think has helped your partner to change his/her eating habits?
- Was there anything or anyone that made this it difficult for you?

- (If yes) How did you manage this difficulty?
- Was there anything or anyone that helped you?
- Did making changes in eating ever cause tension between you and your partner?
- What types of food are being eaten, are they aware when preparing and cooking foods, are they health conscious
- Recovery process, what has this been like, how much time is spent doing activities together (cooking, physical activity)

Exercise/Physical activity

2 - Can you tell me about any changes in exercise/physical activity habits that you and your partner have made since the procedure?

Probes:

- How did you decide what type of exercise to do?
- Have you done anything that you think has helped your partner to change his/her exercise/physical activity levels?
- Was there anything or anyone that made this it difficult for you?
- (If yes) How did you manage this difficulty?
- Was there anything or anyone that helped you?
- Have you any experience of going to cardiac rehabilitation classes?
- Did making changes in exercise/physical activity levels ever cause tension between you and your partner?
- Did you attend CR with your partner?
- Do you feel Cr has been effective to attend for your partner?

Medications

2 - Can you tell me about anything you have done to help your partner manage his/her medications?

Probes:

- Was there anything that made it difficult for you to support your partner with managing medications?
- (If yes) Can you tell me how you managed this difficulty?
- Was there anything that helped you to support your partner with managing medications?

- Did issues around medications ever cause tension between you and your partner?

Cigarette smoking (if relevant)

2 - Can you tell me how your partner is doing with managing his/her cigarette smoking?

Probes:

- Have you played a part in helping them manage their cigarette smoking?
- Was there anything that made it difficult for you to support your partner with managing cigarette smoking?
- (If yes) Can you tell me how you managed this difficulty?
- Was there anything that helped you to support your partner with managing cigarette smoking?
- Did issues around cigarette smoking ever cause tension between you and your partner?

Personal

2 - Can you tell me how you feel that your partner's heart condition has affected you?

Probe:

- How has it affected your role as a partner?
- How has it affected your family?
- Do you have any particular worries or concerns?
- Is there anything or anyone who has supported you through this time?
- Was there anything that would have helped you that you did not get?
- Coping with life on daily basis – are you conscious of condition?
- Have you felt supported/relationships/family/friends
- Social relationships
- Employment

Closing

2 - Is there anything you would like to add?

Probe:

- Are there any improvements that could be made to the care you/partner have had?
- Was there anything aspect of your care that was especially good?

To finish, we are going to use our findings to improve the service and develop new information. We value your opinion as somebody who has experience of the service we provide.

- Would you and your partner be willing to be contacted to ask your opinion about any changes that we have planned for the service? Yes/No
- Would you like a summary of the study findings sent to you? Yes/No

11.11 TOPIC GUIDES: HEALTHCARE PROFESSIONAL

HCP TOPIC GUIDE SCHEDULE

TAKE

- Consent forms
- Audio Recorder
- Quotes
- Refreshments

STRUCTURE

- Present quotes
- Targeted points (prompts and pick up key points and elaborate)
- Questions to HCP’s

CONSIDER

- Layout of room

OBSERVER ROLE

- Observer will take notes of HCP focus group session

AIM &CONSIDERATIONSS OF FOCUS GROUP

- Keep it flowing when contentions arise
- Set scene by asking everyone to introduce themselves so voices can be recognised easily
- Ask everyone to be considerate of others talking, take turns
- Keep topic central to discussion
- Observe body language
- Adhere to confidentiality and respect what others say in group
- Collect a variety of views
- Collect a depth of HCP opinions and information
- Be aware that people may be shy
- Be aware that dishonest views may arise due to a focus group

- Generate perspectives to build a rapport
- Be aware of group tensions and disagreements amongst group members

START

Welcome to the focus group. Thank you for taking the time to attend. I have asked you to come along today to share your expertise about an important health issue in the west midlands community led by myself.

Introduce the observer

I want to discuss your views about some issues that affect Pakistani heart failure patients and their carers. There are no right or wrong answers; I am interested in differing points of view. Please share your views, both positive and negative. Please speak clearly and one at a time as I am recording and I want to note every comment so that I don't miss anything. My role is to ask questions and listen; I won't be joining in any conversations. Please talk freely. Let's introduce ourselves and begin.

All names are used on a 1st name basis and recording of focus group will take place, transcripts will be kept anonymous.

SHOW QUOTES … & ASK

- Elaborate
- What are your views?
- Do you observe this?
- Is this reflective of your clinical practice?
- How do you address this?
- What does this mean for your practice?
- What are your professional perceptions of these patients' views?
- Is this representative of the Pakistani HF patients and their carers?
- Does your practice resemble consistency with this?
- Part of my research is to recommend the development an effective education programme, what do you feel are the appropriate aspects of a tool? What should be included to address the needs of Pakistani patients and carers?

Dietician:

- How can Pakistani HF patients and their carers be best informed of their palette?

Imam:

- Faith is a strong aspect of a Muslim Pakistani HF patient’s life and their carers, how best can they incorporate this into health?

Pharmacist:

- How important is it that patients understand their medications?

HF Nurse/GP:

- How would the term HF be explained to a patient and their carer and what is key to Pakistani HF patient’s management?

Physiologist:

- Activity is key in rehabilitation, what can patients to keep exercise incorporated as part of their lifestyle?

Have we missed anything?

Are there any further information or questions?

Thank you for coming, if you have any questions please feel free to ask me.

11.12 PARTICIPANT CONSENT FORMS

Sandwell & West Birmingham Hospitals NHS

NHS Trust

BIRMINGHAM CITY University

Birmingham City University

Patient Consent Form

Research Study Number: Patient Identification Number:

Title of Project: Title of Project: A Cross-Gender Comparative Understanding of the Needs of Pakistani Chronic Heart Failure Patients and Their Carers –

A Qualitative Study

Please initial boxes

1. I confirm that I have read and understand the information sheet dated for the above research study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from the NHS trust and Birmingham City University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I understand that I will participate in audio-taped interviews and publication of direct quotations from the interview transcripts will be anonymised. ☐

5. I agree to allow medical information about my family to be entered on a confidential computer database. ☐

6. If further medical information is requested by members of the project team. I agree to be contacted again for this purpose. ☐

7. I understand that my on completion of the study the database ☐

containing anonymised profiles and interview tapes and questionnaires will be destroyed, in accordance with the 1998 Data Protection Act.

8. If I lost the capacity to consent during the study I would be withdrawn from it ☐

and the data already collected retained.

9. I agree to take part in the above research study. ☐

Name of Participant Date Signature(s)

Name of Person taking consent Date Signature

Researcher Date Signature

11.13 CARER CONSENT FORMS

Birmingham City University

Carer Consent Form

Research Study Number: Patient Identification Number:

Title of Project: A Cross-Gender Comparative Understanding of the Needs of Pakistani Chronic Heart Failure Patients and Their Carers –

A Qualitative Study

Please initial boxes

10. I confirm that I have read and understand the information sheet dated for the above research study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

11. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

12. I understand that relevant sections of any of my medical notes and data collected during the study, may be looked at by responsible individuals from the NHS trust and Birmingham City University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

13. I understand that I will participate in audio-taped interviews and publication of direct quotations from the interview transcripts will be anonymised. ☐

14. If further medical information is requested by members of the project team. I agree to be contacted again for this purpose. ☐

15. I understand that on completion of the study the database containing anonymised profiles and interview tapes and questionnaires will be destroyed, in accordance with the 1998 Data Protection Act. ☐

☐

16. If I lost the capacity to consent during the study I would be withdrawn from it and the data already collected retained.

☐

17. I agree to take part in the above research study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

Researcher Date Signature

11.14 HEALTHCARE PROFESSIONAL CONSENT FORMS

Birmingham City University

HCP Consent Form

Research Study Number: Identification Number:

Title of Project: A Cross-Gender Comparative Understanding of the Needs of Pakistani Chronic Heart Failure Patients and Their Carers –

A Qualitative Study

Please initial boxes

18. I confirm that I have read and understand the invitation letter dated for the above research study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

19. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

20. I understand that I will participate in audio-taped interviews and publication ☐

of direct quotations from the interview transcripts will be anonymised.

21. I understand that my on completion of the study the database ☐

containing anonymised profiles and interview tapes and questionnaires will be destroyed, in accordance with the 1998 Data Protection Act.

☐

22. I agree to take part in the above research study.

____________________________ ____________________ __________________________
Name of Participant Date Signature

____________________________ ____________________ __________________________
Name of Person taking consent Date Signature

____________________________ ____________________ __________________________
Researcher Date Signature

11.15 STUDY TEAM CONTACT DETAILS

Birmingham City University

A Cross-Gender Comparative Understanding of the Needs of Pakistani Chronic Heart Failure Patients and Their Carers – A Qualitative Study.

This study aims to explore the self management experiences of heart failure patients and their carers. Recruitment of patients will take place from City Hospital, Wolverhampton Royal Hospital and Russell Hall hospital

Study Team Contact Details:

Rifat Yusuf (PhD Research Student)

rifat.yusuf@mail.bcu.ac.uk/ 0121 2024539

Professor Elaine Denny (Supervisor)

Dr Salim Khan (Supervisor)

Jane Powell (Research Nurse)

11.16 SCHEDULING INTERVIEW LETTER

Birmingham City University

Date

Re: Scheduling Interview

Dear

I would like to arrange an interview with you and have left a few messages for you but have not managed to get in touch. Please ignore this letter if I have subsequently got hold of you and we have already made a plan for my next visit.

I would like to arrange a visit, at your home, at a time that suits you. Depending on your schedule, it would be very helpful if I could see you this week, the week beginning …. …. 2012

If possible would you contact me to confirm a time and date that suits you. I will try and call again to make sure you received your letter.

With best wishes

Rifat Yusuf

PhD Research Student

Work (0121) 2024539

Mobile - 07712134984

11.17 ADDITIONAL PATIENT INFORMATION/DEMOGRAPHICS

Birmingham City University

Participant ID:	
Gender	1. Male 2. Female
Date of diagnosis of HF	
Age in years	
Educational Level	1. Never attended school 2. Primary school 3. Some high school 4. Completed high school 5. Tertiary education
Marital status	1. Living alone 2. Married or cohabiting
Current Employment/Occupation	
Has patient attended cardiac rehabilitation?	1. Yes

	2. No
Height & Weight	1. 2.
Total Cholesterol (mmol/L)	
Smoking status	0. Never smoked 1. Ex smoker 2. Current smoker 3. Non smoker, history unknown 9. Unknown
Hypertension	0. No 1. Yes 9. Unknown
Family history of CHD	0. No 1. Yes 9. Unknown
Hypertension	0. No 1. Yes 9. Unknown
Hypercholesterolemia	0. No 1. Yes 9. Unknown
Previous cardiac history	1. Angina

	2. MI 3. Other
Prescribed Medications	1. Aspirin 2. Beta-blocker 3. Statin 4. Ace

11.18 ACADEMIC SPONSORSHIP AND INDEMNITY

AON
Commercial Insurance

158 Edmund Street
Birmingham
B3 2HB
Tel: 0121 253 3100
Fax: 0121 212 1200

TO WHOM IT MAY CONCERN

DATE AS POSTMARK

Dear Sirs,

BIRMINGHAM CITY UNIVERSITY and/or subsidiary companies and/or affiliated companies and/or associated companies for their respective rights and interests.

We act as Insurance Brokers to the above client. In accordance with our client's instructions, we have pleasure in providing below details of their current Public/Products Liability Insurance cover: -

DESCRIPTION OF INSURANCES	**EMPLOYERS LIABILITY**
INSURERS	Allianz
POLICY NUMBER	SZ21708573
PERIOD OF INSURANCE	From 1st August 2011 to 31st July 2012 both days inclusive
LIMIT OF INDEMNITY	£25,000,000 any one event

DESCRIPTION OF INSURANCES	**PUBLIC/PRODUCTS LIABILITY**
INSURERS	Allianz
POLICY NUMBER	SZ21708573
PERIOD OF INSURANCE	From 1st August 2011 to 31st July 2012 both days inclusive
LIMIT OF INDEMNITY	£15,000,000 any one event

Cover includes the usual extensions including Indemnity to Principals.

DESCRIPTION OF INSURANCES	**EXCESS PUBLIC/PRODUCTS LIABILITY**
INSURERS	Chartis Insurance
POLICY NUMBER	24632765
PERIOD OF INSURANCE	From 1st August 2011 to 31st July 2012 both days inclusive
LIMIT OF INDEMNITY	£10,000,000 any one event

Cover includes the usual extensions including Indemnity to Principals.

Continued…

INSURANCES	**PROFESSIONAL INDEMNITY**
INSURERS	ROYAL & SUN ALLIANCE
POLICY NUMBER	RKK540601
PERIOD OF INSURANCE	From 1st August 2011 to 31st July 2012 both days inclusive
LIMIT OF INDEMNITY	£5,000,000 for all claims in the aggregate notified during any period of Insurance
PRINCIPAL EXTENSIONS	Cover extends to include liability in connection with or arising out of all persons seconded to the Insured to work on specific projects as designated by the Policyholder.

The information supplied should not be understood as providing advice to you or anyone else on any decision that is under consideration. The reader of this letter is responsible for any assumptions they make as to the coverage afforded by the Insurances, which may be subject to important conditions and/or exclusions.

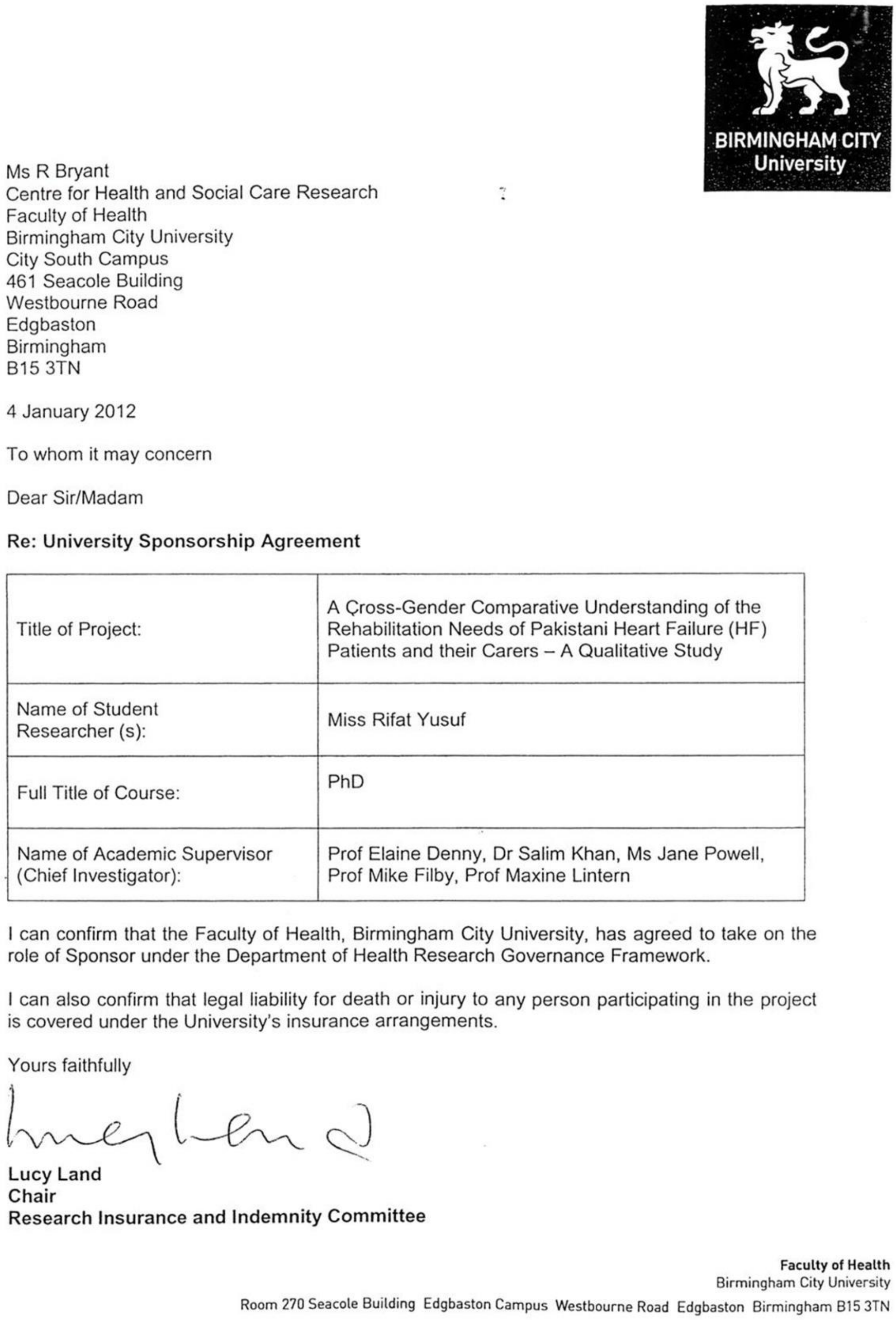
We accept no obligation to inform you or any other person should any of the Insurances be cancelled, assigned or changed in such manner as to affect the accuracy of this document. Unless we specifically agree otherwise in writing, and to the fullest extent permitted by law, we do not accept any liability to anyone other than our client for the content of this letter and its attachments.

Yours faithfully
For & on behalf of Aon Limited

Alexandra Cooper
Client Service Advisor

☎ Direct Dial: 0121 253 3093
E-mail: alexandra.cooper@aon.co.uk

11.19 UNIVERSITY SPONSORSHIP AGREEMENT



BIRMINGHAM CITY
University

Ms R Bryant
Centre for Health and Social Care Research
Faculty of Health
Birmingham City University
City South Campus
461 Seacole Building
Westbourne Road
Edgbaston
Birmingham
B15 3TN

4 January 2012

To whom it may concern

Dear Sir/Madam

Re: University Sponsorship Agreement

Title of Project:	A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and their Carers – A Qualitative Study
Name of Student Researcher (s):	Miss Rifat Yusuf
Full Title of Course:	PhD
Name of Academic Supervisor (Chief Investigator):	Prof Elaine Denny, Dr Salim Khan, Ms Jane Powell, Prof Mike Filby, Prof Maxine Lintern

I can confirm that the Faculty of Health, Birmingham City University, has agreed to take on the role of Sponsor under the Department of Health Research Governance Framework.

I can also confirm that legal liability for death or injury to any person participating in the project is covered under the University's insurance arrangements.

Yours faithfully

Lucy Land
Chair
Research Insurance and Indemnity Committee

Faculty of Health
Birmingham City University
Room 270 Seacole Building Edgbaston Campus Westbourne Road Edgbaston Birmingham B15 3TN

11.20 NHS R&D IRAS ETHICS RESEARCH PASSPORT/APPROVAL (NIHR CRN)

HEART of ENGLAND
NHS Foundation Trust

Research & Development Directorate

midru
Medical Innovation Development Research Unit
Office Hours (Mon-Fri): 09.00 – 17.00
Tel: 0121 424 1633
Fax: 0121 424 3167
Head of Research & Innovation: Bethan Bishop
R&D Manager - Governance & Operations: Elizabeth Adey
R&D Manager - Finance & Facilities: Rachel Ward
Please send e-mails via firstname.surname@heartofengland.nhs.uk

Birmingham Heartlands Hospital
Bordesley Green East
Birmingham B9 5SS

Tel: 0121 424 2000
Fax: 0121 424 2200

24th July 2012

Ms Rifat Yusuf
Birmingham City University
223 Ravensbury House
Westbourne Campus
Edgbaston
Birmingham
B15 3TN

Dear Ms Yusuf

***R&D Code:* 2011131CD *Re: Study title:* A CrossGender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers â€“ A Qualitative Study.**

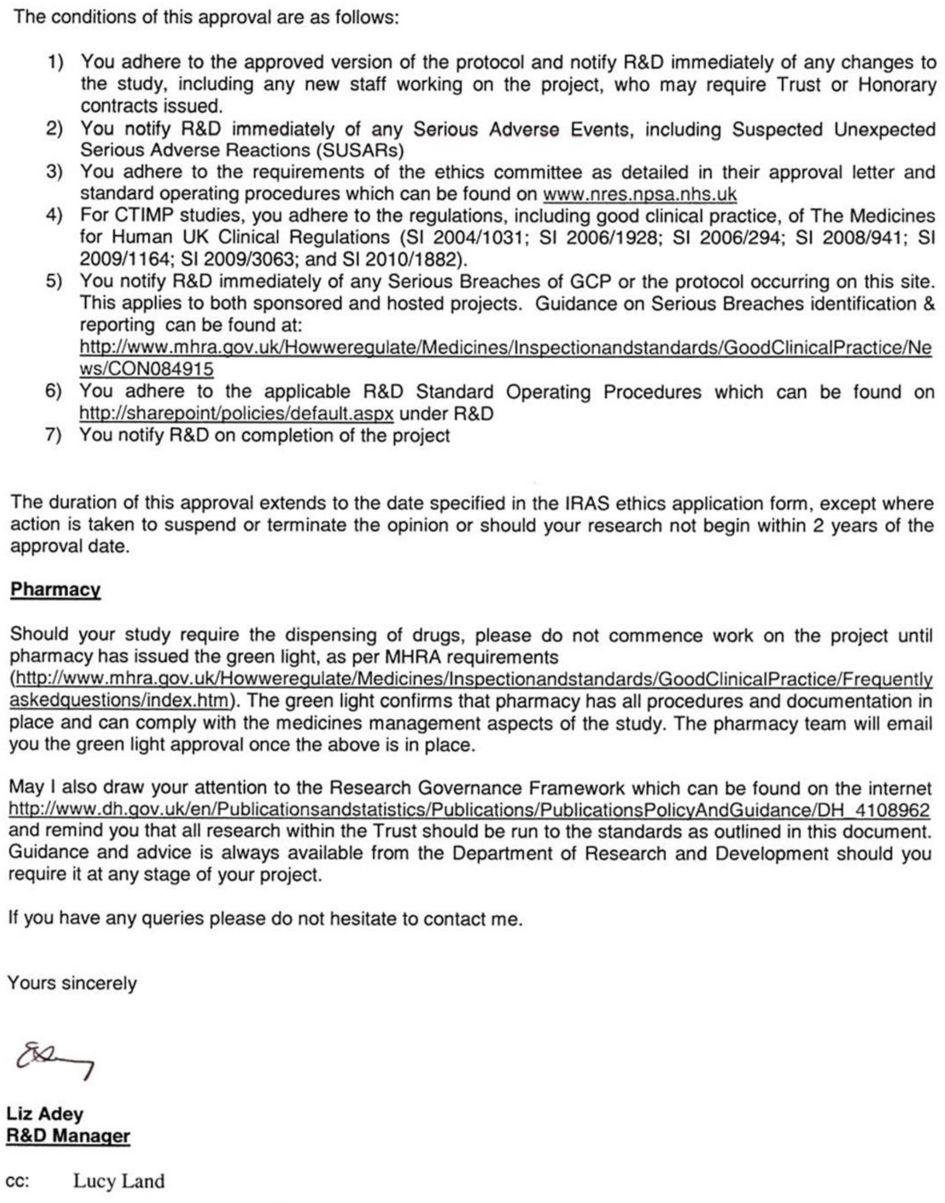
I am pleased to inform you that the R&D review of the above project is now complete and has been formally approved to be undertaken at the following sites within Heart of England NHS Foundation Trust.

Birmingham Heartlands Hospital	Research Site
Solihull Hospital	Research Site

The following documents were reviewed:

Document/Version/Date	
Protocol	Version 1.1 21 February 2012
PIS & Consent	Patient Version 1.1 21 February 2012
PIS	Carer Version 1.1 21 February 2012
Consent	Carer Version 1.2 13 March 2012
NHS NRES Application Form	R. Yusuf 16 January 2012
NRES Site Specific Information Form	R. Yusuf 03 May 2012
NRES Approval Letter	15th March 2012
Letter of Invitation	Patient Version 1.1 21 February 2012
Letter of Invitation	Carer Version 1.0 21 February 2012
Letter of invitation	Healthcare Professional, Version 1.1 21 February 2012
Sponsor Letter	4th January 2012
Insurance Letter	Expires 31/07/2012

… continued …



The conditions of this approval are as follows:

1) You adhere to the approved version of the protocol and notify R&D immediately of any changes to the study, including any new staff working on the project, who may require Trust or Honorary contracts issued.
2) You notify R&D immediately of any Serious Adverse Events, including Suspected Unexpected Serious Adverse Reactions (SUSARs)
3) You adhere to the requirements of the ethics committee as detailed in their approval letter and standard operating procedures which can be found on www.nres.npsa.nhs.uk
4) For CTIMP studies, you adhere to the regulations, including good clinical practice, of The Medicines for Human UK Clinical Regulations (SI 2004/1031; SI 2006/1928; SI 2006/294; SI 2008/941; SI 2009/1164; SI 2009/3063; and SI 2010/1882).
5) You notify R&D immediately of any Serious Breaches of GCP or the protocol occurring on this site. This applies to both sponsored and hosted projects. Guidance on Serious Breaches identification & reporting can be found at: http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/News/CON084915
6) You adhere to the applicable R&D Standard Operating Procedures which can be found on http://sharepoint/policies/default.aspx under R&D
7) You notify R&D on completion of the project

The duration of this approval extends to the date specified in the IRAS ethics application form, except where action is taken to suspend or terminate the opinion or should your research not begin within 2 years of the approval date.

Pharmacy

Should your study require the dispensing of drugs, please do not commence work on the project until pharmacy has issued the green light, as per MHRA requirements (http://www.mhra.gov.uk/Howweregulate/Medicines/Inspectionandstandards/GoodClinicalPractice/Frequentlyaskedquestions/index.htm). The green light confirms that pharmacy has all procedures and documentation in place and can comply with the medicines management aspects of the study. The pharmacy team will email you the green light approval once the above is in place.

May I also draw your attention to the Research Governance Framework which can be found on the internet http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962 and remind you that all research within the Trust should be run to the standards as outlined in this document. Guidance and advice is always available from the Department of Research and Development should you require it at any stage of your project.

If you have any queries please do not hesitate to contact me.

Yours sincerely

Liz Adey
R&D Manager

cc: Lucy Land

Sandwell & West Birmingham Hospitals NHS
NHS Trust

RESEARCH AND DEVELOPMENT

C E Clarke, BSc, MD, FRCP — R&D Director
J Bell, BSc, MSc, PhD — Head of R&D
S Baxter, BSc (Hons) — RM&G Manager
B Baines BA (Hons) — R&D Administrator

(0121) 507 4811
(0121) 507 4092
(0121) 507 4091
Fax (0121) 507 4945

Arden House
City Hospital
Dudley Road
Birmingham
B18 7QH

CEC/SB/R&D Ref: 12EDUC05
13 July 2012 - Reissued to include amend Carer Invitation letter to V1

04 April 2012

Miss Rifat Yusuf
PhD Research Student
Birmingham City University
223 Ravensbury House
Westbourne Campus
Edgbaston
B15 3TN

Dear Miss Yusuf,

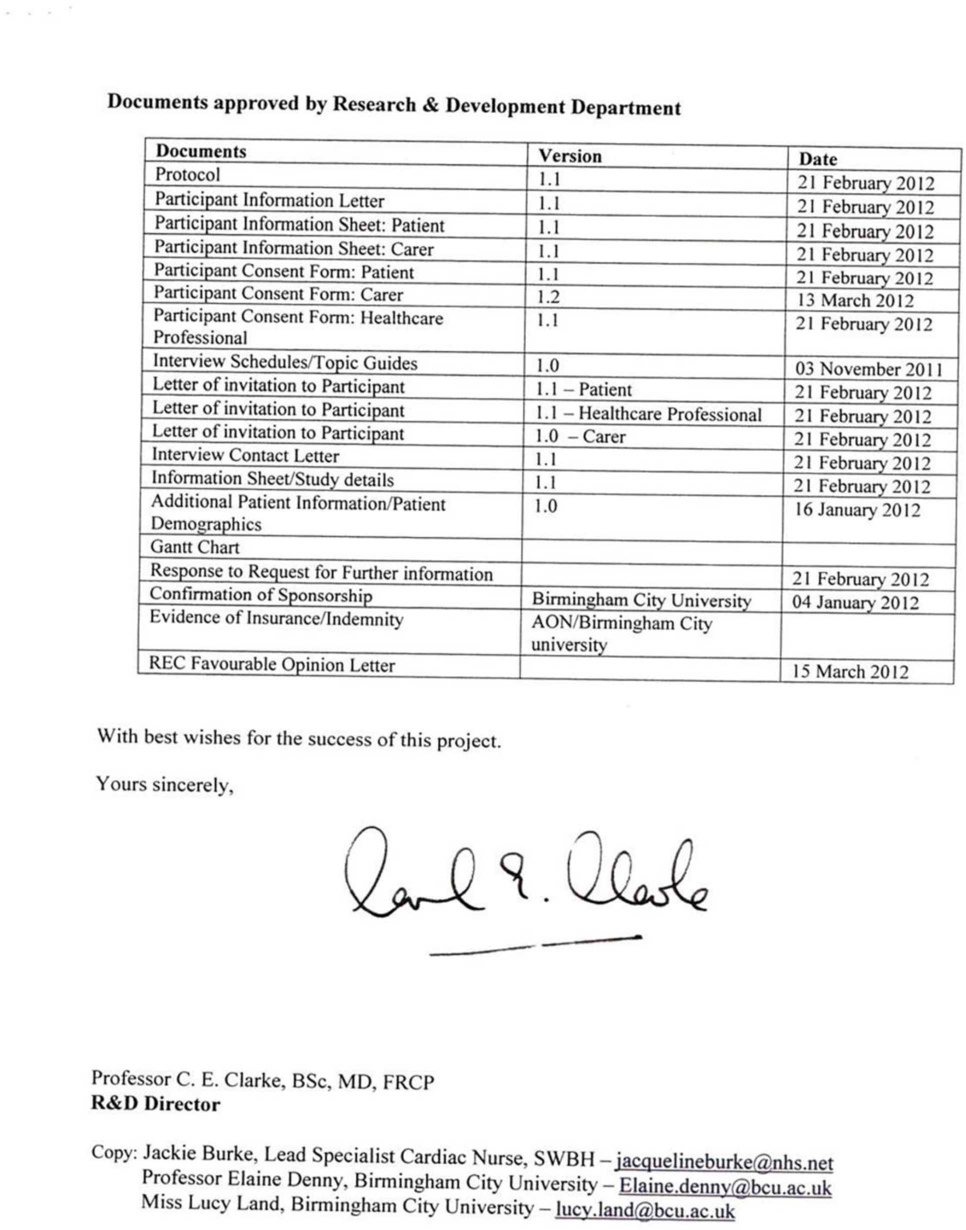
Study Title:	**A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – a Qualitative Study**
REC Ref:	**12/WM/0035**

Thank you for submitting your request to conduct this research in the Trust.

Conditions of Approval

I am pleased to inform you that the request is approved for the project you describe, and that your research can proceed subject to the following conditions:

1. That you keep an up to date and accurate record of your research in a study file, and that you make this file and other records available for audit by the Research and Development Office when requested.
2. That you inform the R&D office of any changes to the study, related documentation or study personnel.
3. That you notify the R&D office of any adverse events arising from this research in accordance with Trust Procedure for safety reporting in research.
4. That where the research continues for more that 1 year, you provide the R&D office with an annual report of your research progress, when approval will be reviewed.



Documents approved by Research & Development Department

Documents	Version	Date
Protocol	1.1	21 February 2012
Participant Information Letter	1.1	21 February 2012
Participant Information Sheet: Patient	1.1	21 February 2012
Participant Information Sheet: Carer	1.1	21 February 2012
Participant Consent Form: Patient	1.1	21 February 2012
Participant Consent Form: Carer	1.2	13 March 2012
Participant Consent Form: Healthcare Professional	1.1	21 February 2012
Interview Schedules/Topic Guides	1.0	03 November 2011
Letter of invitation to Participant	1.1 – Patient	21 February 2012
Letter of invitation to Participant	1.1 – Healthcare Professional	21 February 2012
Letter of invitation to Participant	1.0 – Carer	21 February 2012
Interview Contact Letter	1.1	21 February 2012
Information Sheet/Study details	1.1	21 February 2012
Additional Patient Information/Patient Demographics	1.0	16 January 2012
Gantt Chart		
Response to Request for Further information		21 February 2012
Confirmation of Sponsorship	Birmingham City University	04 January 2012
Evidence of Insurance/Indemnity	AON/Birmingham City university	
REC Favourable Opinion Letter		15 March 2012

With best wishes for the success of this project.

Yours sincerely,

Carl E. Clarke

Professor C. E. Clarke, BSc, MD, FRCP
R&D Director

Copy: Jackie Burke, Lead Specialist Cardiac Nurse, SWBH – jacquelineburke@nhs.net
Professor Elaine Denny, Birmingham City University – Elaine.denny@bcu.ac.uk
Miss Lucy Land, Birmingham City University – lucy.land@bcu.ac.uk

RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

After ethical review – guidance for sponsors and investigators

This document sets out important guidance for sponsors and investigators on the conduct and management of research with a favourable opinion from a NHS Research Ethics Committee. Please read the guidance carefully. A failure to follow the guidance could lead to the committee reviewing its opinion on the research.

1. Further communications with the Research Ethics Committee

1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as “the Committee”) are the personal responsibility of the Chief Investigator.

2. Commencement of the research

2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2 The research must not commence at any site until the local Principal Investigator (PI) or research collaborator has obtained management permission or approval from the organisation with responsibility for the research participants at the site.

2.3 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay

2.4 Should the research not commence within 24 months, the Committee may review its opinion.

3. Duration of ethical approval

3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

3.2 Where the research involves the use of "relevant material" for the purposes of the Human Tissue Act 2004, authority to hold the material under the terms of the ethical approval applies until the end of the period declared in the application and approved by the Committee.

4. Progress reports

4.1 Research Ethics Committees are expected to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be in the format prescribed by NRES and published on the website (see www.nres.npsa.nhs.uk/applicants/after-ethical-review/).

4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5. Amendments

5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

(a) the safety or physical or mental integrity of the trial participants
(b) the scientific value of the trial
(c) the conduct or management of the trial.

5.3 Notices of amendment should be in the format prescribed by NRES and published on the website, and should be personally signed by the Chief Investigator. The agreement of the sponsor should be sought before submitting the notice of amendment.

5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

6. Changes to sites

Management permission (all studies)

6.1 For all studies, management permission should be obtained from the host organisation where it is proposed to:

- include a new site in the research, not included in the list of proposed research sites in the original REC application
- appoint a new PI or Local Collaborator at a research site
- make any other significant change to the conduct or management of a research site.

In the case of any new NHS site, the Site-Specific Information (SSI) Form should be submitted to the R&D office for review as part of the R&D application.

Site-specific assessment (where required)

6.2 The following guidance applies only to studies requiring site-specific assessment (SSA) as part of ethical review.

6.3 In the case of *NHS/HSC sites*, SSA responsibilities are undertaken on behalf of the REC by the relevant R&D office as part of the research governance review. The Committee's favourable opinion for the study will apply to any new sites and other changes at sites provided that management permission is obtained. There is no need to notify the Committee (or any other REC) about new sites or other changes, or to provide a copy of the SSI Form.

6.4 Changes at *non-NHS sites* require review by the local REC responsible for site-specific assessment (SSA REC). Please submit the SSI Form (or revised SSI Form as appropriate) to the SSA REC together with relevant supporting documentation. The SSA REC will advise the main REC whether it has any objection to the new site/PI or other change. The main REC will notify the Chief Investigator and sponsor of its opinion within a maximum of 35 days from the date on which a valid SSA application has been received by the SSA REC.

Studies not requiring SSA

6.5 For studies designated by the Committee as not requiring SSA, there is no requirement to notify the Committee of the inclusion of new sites or other changes at sites, either for NHS or non-NHS sites. However, management permission should still be obtained from the responsible host organisation (see 6.1 above).

7. Urgent safety measures

7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

8. Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

(a) results in death
(b) is life-threatening
(c) requires hospitalisation or prolongation of existing hospitalisation
(d) results in persistent or significant disability or incapacity
(e) consists of a congenital anomaly or birth defect
(f) is otherwise considered medically significant by the investigator.

8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

8.3 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by NRES and published on the website.

8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.

8.5 Reports should not be sent to other RECs in the case of multi-site studies.

9. Conclusion or early termination of the research

9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website.

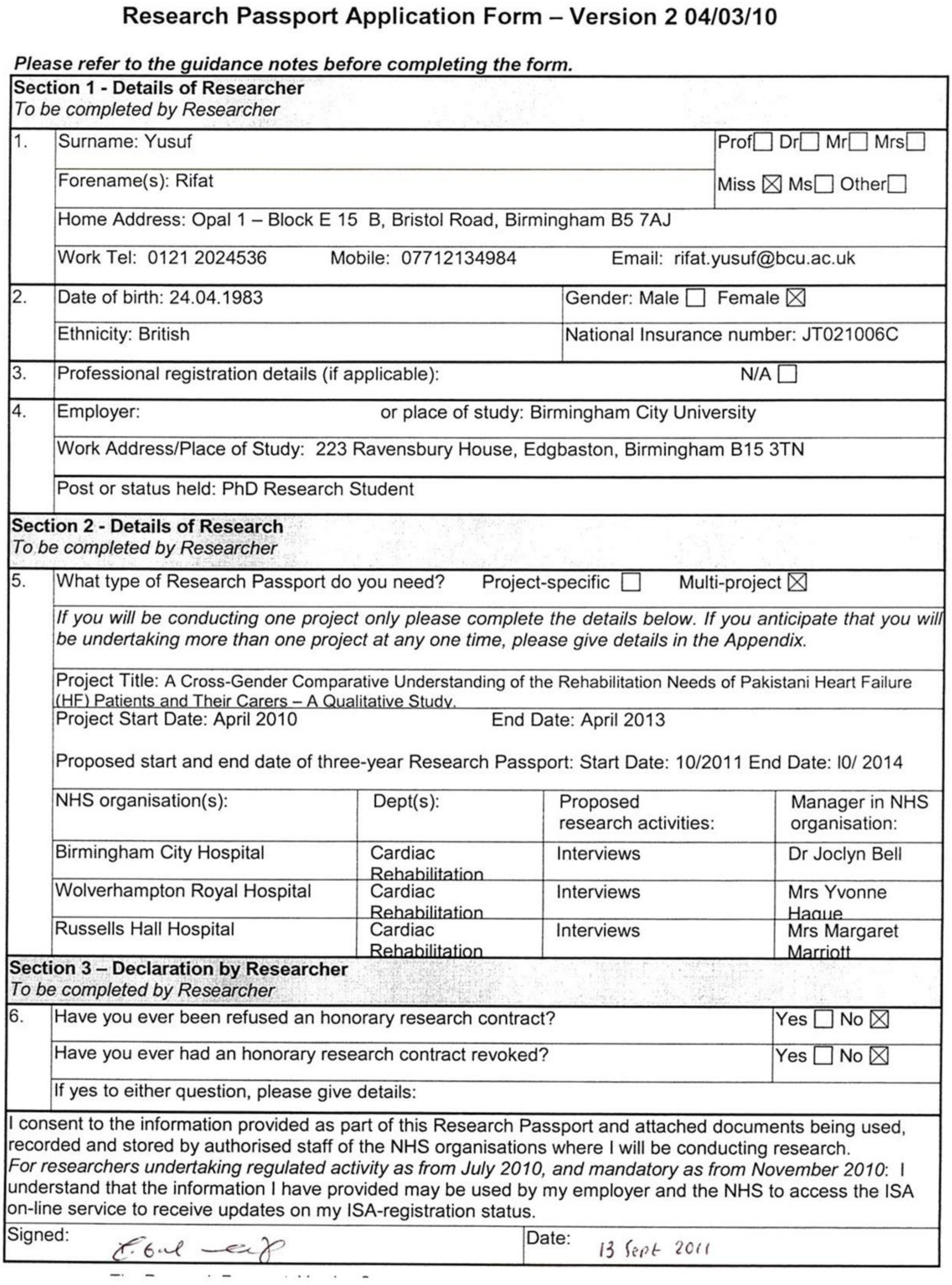
10. Final report

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

11. Review of ethical opinion

11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.



Research Passport Application Form – Version 2 04/03/10

Please refer to the guidance notes before completing the form.

Section 1 - Details of Researcher
To be completed by Researcher

1.	Surname: Yusuf	Prof☐ Dr☐ Mr☐ Mrs☐
	Forename(s): Rifat	Miss ☒ Ms☐ Other☐
	Home Address: Opal 1 – Block E 15 B, Bristol Road, Birmingham B5 7AJ	
	Work Tel: 0121 2024536 Mobile: 07712134984 Email: rifat.yusuf@bcu.ac.uk	
2.	Date of birth: 24.04.1983	Gender: Male ☐ Female ☒
	Ethnicity: British	National Insurance number: JT021006C
3.	Professional registration details (if applicable):	N/A ☐
4.	Employer: or place of study: Birmingham City University	
	Work Address/Place of Study: 223 Ravensbury House, Edgbaston, Birmingham B15 3TN	
	Post or status held: PhD Research Student	

Section 2 - Details of Research
To be completed by Researcher

5. What type of Research Passport do you need? Project-specific ☐ Multi-project ☒

If you will be conducting one project only please complete the details below. If you anticipate that you will be undertaking more than one project at any one time, please give details in the Appendix.

Project Title: A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study.

Project Start Date: April 2010 End Date: April 2013

Proposed start and end date of three-year Research Passport: Start Date: 10/2011 End Date: I0/ 2014

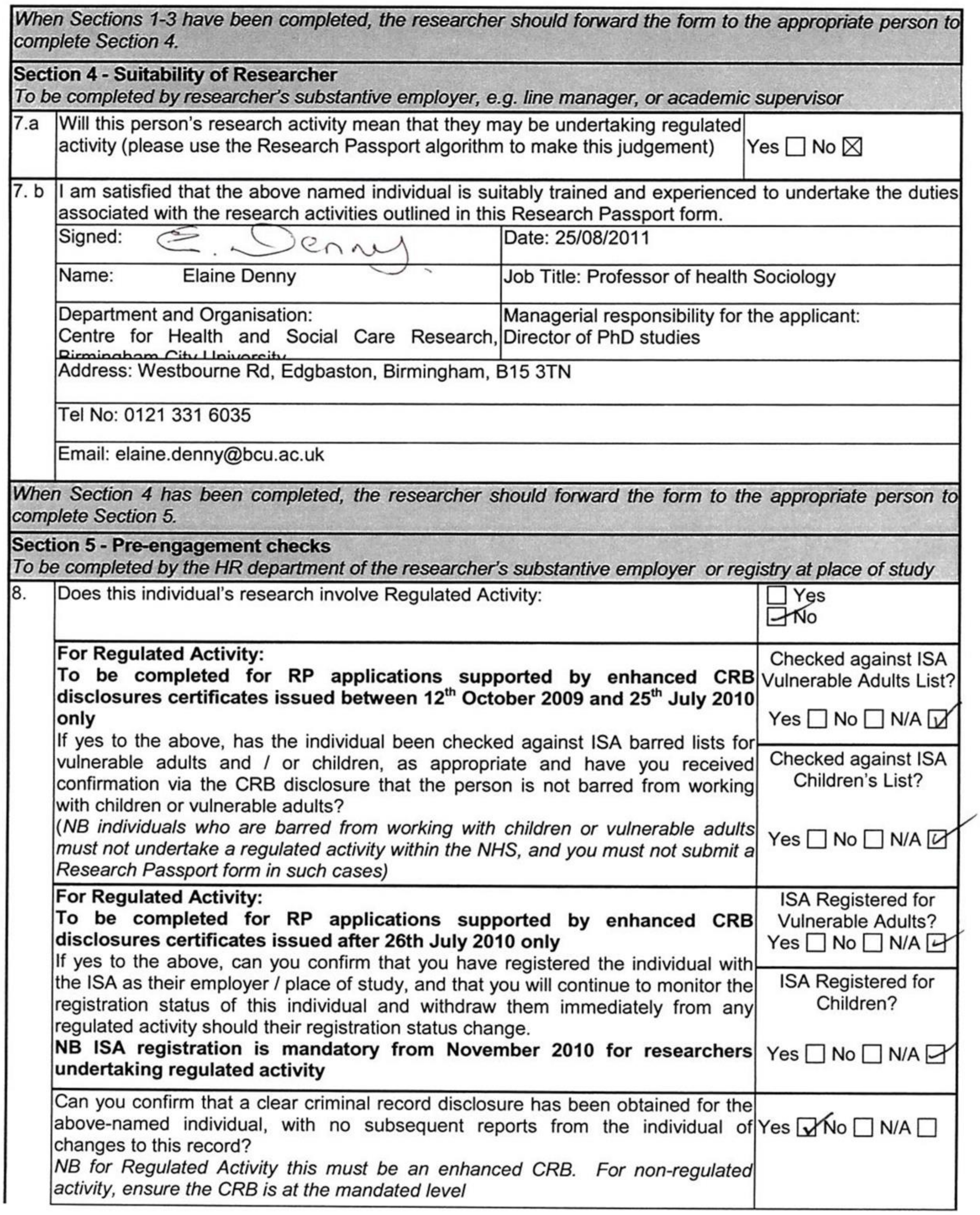
NHS organisation(s):	Dept(s):	Proposed research activities:	Manager in NHS organisation:
Birmingham City Hospital	Cardiac Rehabilitation	Interviews	Dr Joclyn Bell
Wolverhampton Royal Hospital	Cardiac Rehabilitation	Interviews	Mrs Yvonne Hague
Russells Hall Hospital	Cardiac Rehabilitation	Interviews	Mrs Margaret Marriott

Section 3 – Declaration by Researcher
To be completed by Researcher

6.	Have you ever been refused an honorary research contract?	Yes ☐ No ☒
	Have you ever had an honorary research contract revoked?	Yes ☐ No ☒
	If yes to either question, please give details:	

I consent to the information provided as part of this Research Passport and attached documents being used, recorded and stored by authorised staff of the NHS organisations where I will be conducting research.
For researchers undertaking regulated activity as from July 2010, and mandatory as from November 2010: I understand that the information I have provided may be used by my employer and the NHS to access the ISA on-line service to receive updates on my ISA-registration status.

Signed: Date: 13 Sept 2011



When Sections 1-3 have been completed, the researcher should forward the form to the appropriate person to complete Section 4.

Section 4 - Suitability of Researcher
To be completed by researcher's substantive employer, e.g. line manager, or academic supervisor

7.a	Will this person's research activity mean that they may be undertaking regulated activity (please use the Research Passport algorithm to make this judgement)	Yes ☐ No ☒

7. b I am satisfied that the above named individual is suitably trained and experienced to undertake the duties associated with the research activities outlined in this Research Passport form.

Signed: E. Denny	Date: 25/08/2011
Name: Elaine Denny	Job Title: Professor of health Sociology
Department and Organisation: Centre for Health and Social Care Research, Birmingham City University	Managerial responsibility for the applicant: Director of PhD studies

Address: Westbourne Rd, Edgbaston, Birmingham, B15 3TN

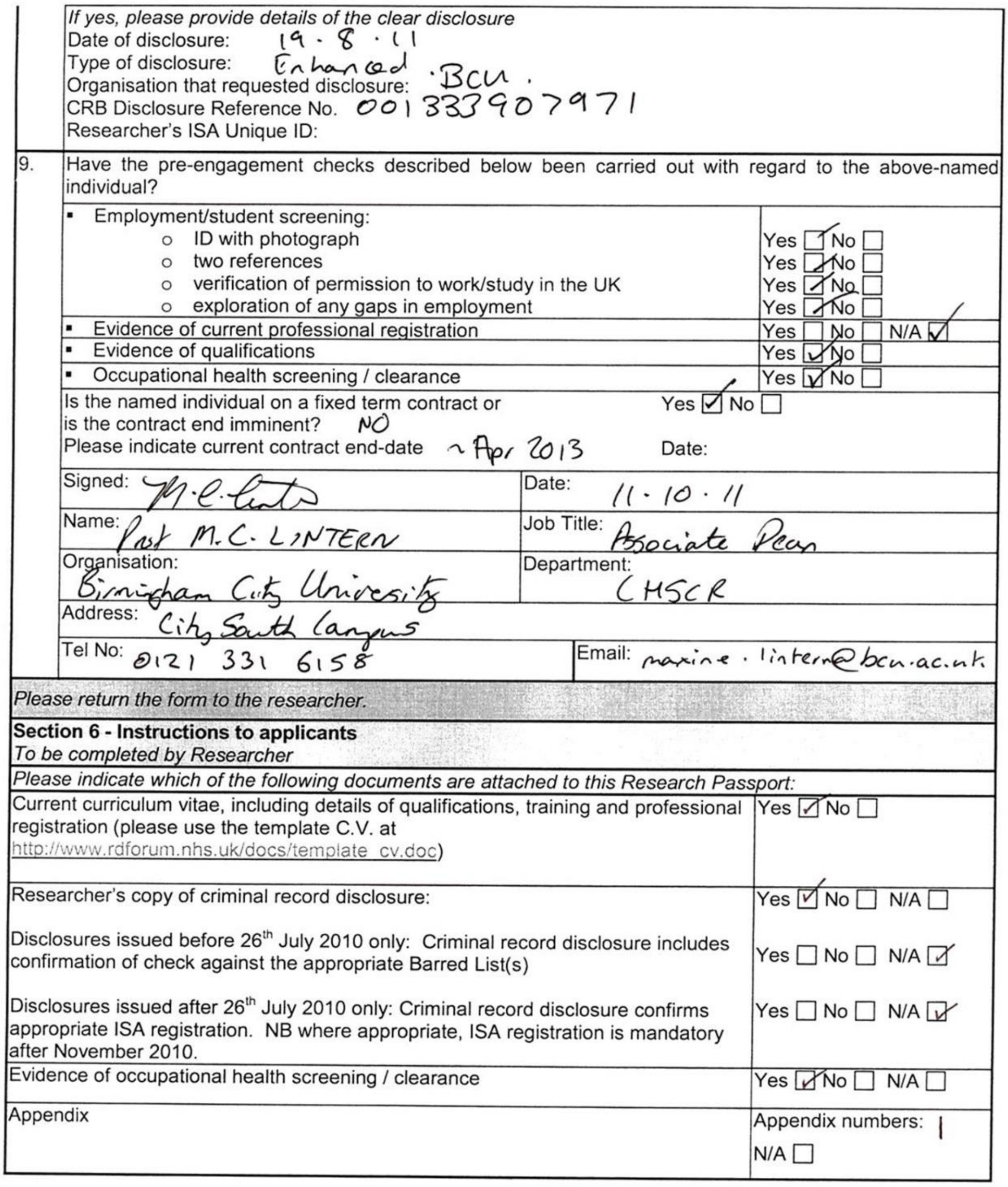
Tel No: 0121 331 6035

Email: elaine.denny@bcu.ac.uk

When Section 4 has been completed, the researcher should forward the form to the appropriate person to complete Section 5.

Section 5 - Pre-engagement checks
To be completed by the HR department of the researcher's substantive employer or registry at place of study

8.	Does this individual's research involve Regulated Activity:	☐ Yes ☑ No
	For Regulated Activity: **To be completed for RP applications supported by enhanced CRB disclosures certificates issued between 12th October 2009 and 25th July 2010 only** If yes to the above, has the individual been checked against ISA barred lists for vulnerable adults and / or children, as appropriate and have you received confirmation via the CRB disclosure that the person is not barred from working with children or vulnerable adults? (*NB individuals who are barred from working with children or vulnerable adults must not undertake a regulated activity within the NHS, and you must not submit a Research Passport form in such cases)*	Checked against ISA Vulnerable Adults List? Yes ☐ No ☐ N/A ☑ Checked against ISA Children's List? Yes ☐ No ☐ N/A ☑
	For Regulated Activity: **To be completed for RP applications supported by enhanced CRB disclosures certificates issued after 26th July 2010 only** If yes to the above, can you confirm that you have registered the individual with the ISA as their employer / place of study, and that you will continue to monitor the registration status of this individual and withdraw them immediately from any regulated activity should their registration status change. **NB ISA registration is mandatory from November 2010 for researchers undertaking regulated activity**	ISA Registered for Vulnerable Adults? Yes ☐ No ☐ N/A ☑ ISA Registered for Children? Yes ☐ No ☐ N/A ☑
	Can you confirm that a clear criminal record disclosure has been obtained for the above-named individual, with no subsequent reports from the individual of changes to this record? *NB for Regulated Activity this must be an enhanced CRB. For non-regulated activity, ensure the CRB is at the mandated level*	Yes ☑ No ☐ N/A ☐



If yes, please provide details of the clear disclosure
Date of disclosure: 19 · 8 · 11
Type of disclosure: Enhanced
Organisation that requested disclosure: · BCU ·
CRB Disclosure Reference No. 001333907971
Researcher's ISA Unique ID:

9. Have the pre-engagement checks described below been carried out with regard to the above-named individual?

- Employment/student screening:	
○ ID with photograph	Yes ☑ No ☐
○ two references	Yes ☑ No ☐
○ verification of permission to work/study in the UK	Yes ☑ No ☐
○ exploration of any gaps in employment	Yes ☑ No ☐
- Evidence of current professional registration	Yes ☐ No ☐ N/A ☑
- Evidence of qualifications	Yes ☑ No ☐
- Occupational health screening / clearance	Yes ☑ No ☐

Is the named individual on a fixed term contract or is the contract end imminent? NO Yes ☑ No ☐
Please indicate current contract end-date ~ Apr 2013 Date:

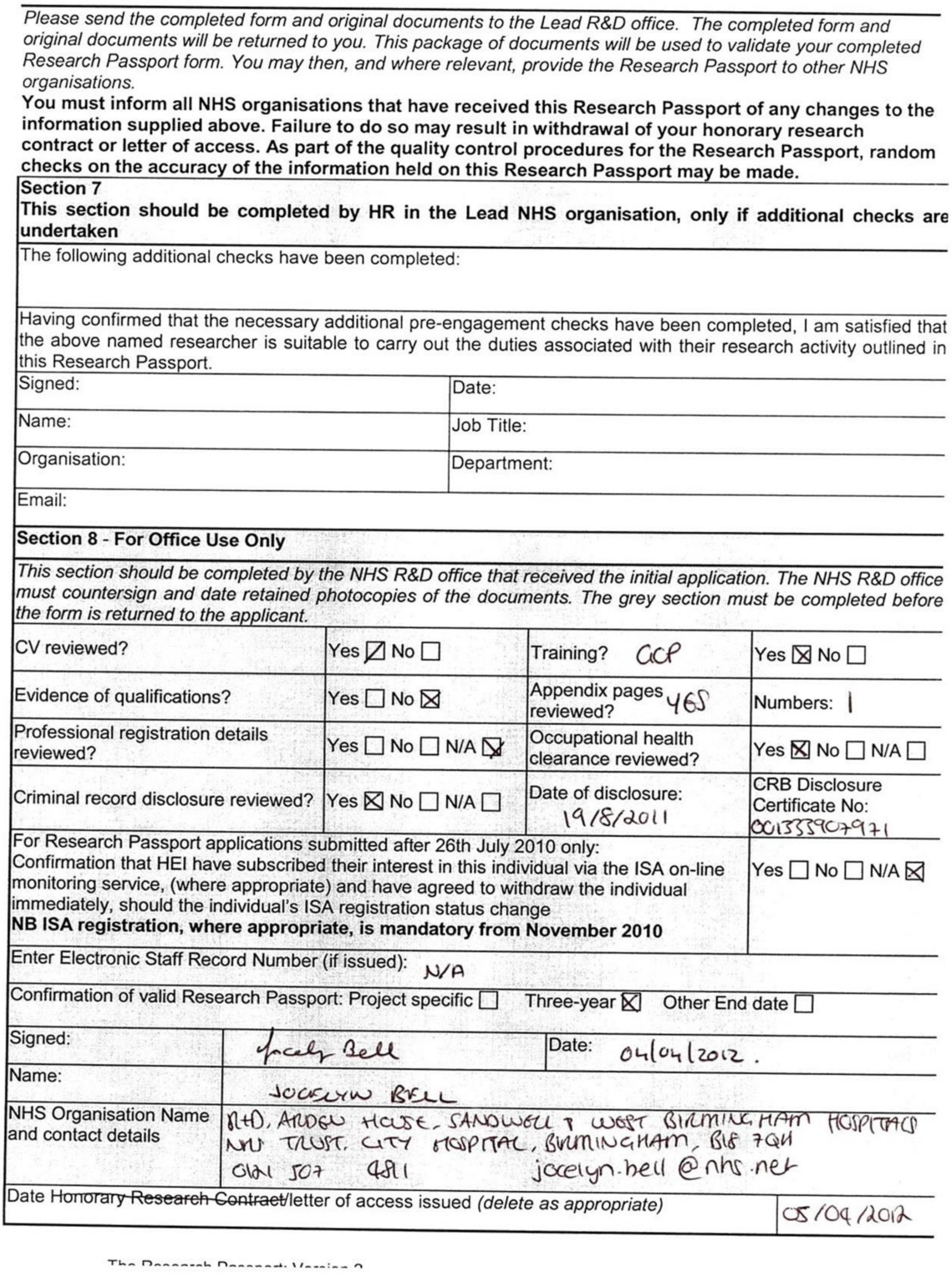
Signed:	Date: 11 · 10 · 11
Name: Prof M.C. LINTERN	Job Title: Associate Dean
Organisation: Birmingham City University	Department: CHSCR
Address: City South Campus	
Tel No: 0121 331 6158	Email: maxine.lintern@bcu.ac.uk

Please return the form to the researcher.

Section 6 - Instructions to applicants
To be completed by Researcher

Please indicate which of the following documents are attached to this Research Passport:

Current curriculum vitae, including details of qualifications, training and professional registration (please use the template C.V. at http://www.rdforum.nhs.uk/docs/template_cv.doc)	Yes ☑ No ☐
Researcher's copy of criminal record disclosure:	Yes ☑ No ☐ N/A ☐
Disclosures issued before 26th July 2010 only: Criminal record disclosure includes confirmation of check against the appropriate Barred List(s)	Yes ☐ No ☐ N/A ☑
Disclosures issued after 26th July 2010 only: Criminal record disclosure confirms appropriate ISA registration. NB where appropriate, ISA registration is mandatory after November 2010.	Yes ☐ No ☐ N/A ☑
Evidence of occupational health screening / clearance	Yes ☑ No ☐ N/A ☐
Appendix	Appendix numbers: 1 N/A ☐



Please send the completed form and original documents to the Lead R&D office. The completed form and original documents will be returned to you. This package of documents will be used to validate your completed Research Passport form. You may then, and where relevant, provide the Research Passport to other NHS organisations.

You must inform all NHS organisations that have received this Research Passport of any changes to the information supplied above. Failure to do so may result in withdrawal of your honorary research contract or letter of access. As part of the quality control procedures for the Research Passport, random checks on the accuracy of the information held on this Research Passport may be made.

Section 7

This section should be completed by HR in the Lead NHS organisation, only if additional checks are undertaken

The following additional checks have been completed:

Having confirmed that the necessary additional pre-engagement checks have been completed, I am satisfied that the above named researcher is suitable to carry out the duties associated with their research activity outlined in this Research Passport.

Signed:	Date:
Name:	Job Title:
Organisation:	Department:
Email:	

Section 8 - For Office Use Only

This section should be completed by the NHS R&D office that received the initial application. The NHS R&D office must countersign and date retained photocopies of the documents. The grey section must be completed before the form is returned to the applicant.

CV reviewed?	Yes ☒ No ☐	Training? GCP	Yes ☒ No ☐
Evidence of qualifications?	Yes ☐ No ☒	Appendix pages reviewed? YES	Numbers: 1
Professional registration details reviewed?	Yes ☐ No ☐ N/A ☒	Occupational health clearance reviewed?	Yes ☒ No ☐ N/A ☐
Criminal record disclosure reviewed?	Yes ☒ No ☐ N/A ☐	Date of disclosure: 19/8/2011	CRB Disclosure Certificate No: 001333907971

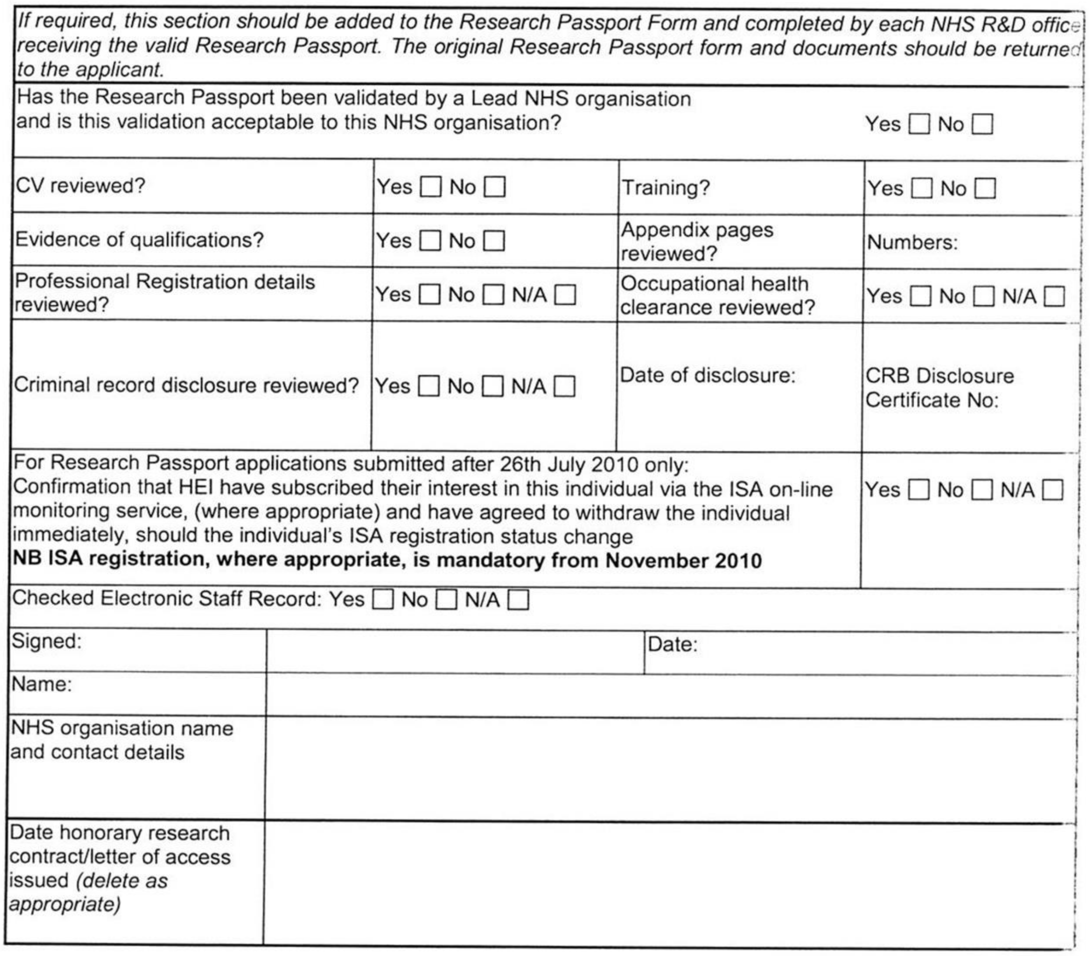
For Research Passport applications submitted after 26th July 2010 only:
Confirmation that HEI have subscribed their interest in this individual via the ISA on-line monitoring service, (where appropriate) and have agreed to withdraw the individual immediately, should the individual's ISA registration status change
NB ISA registration, where appropriate, is mandatory from November 2010
Yes ☐ No ☐ N/A ☒

Enter Electronic Staff Record Number (if issued): N/A

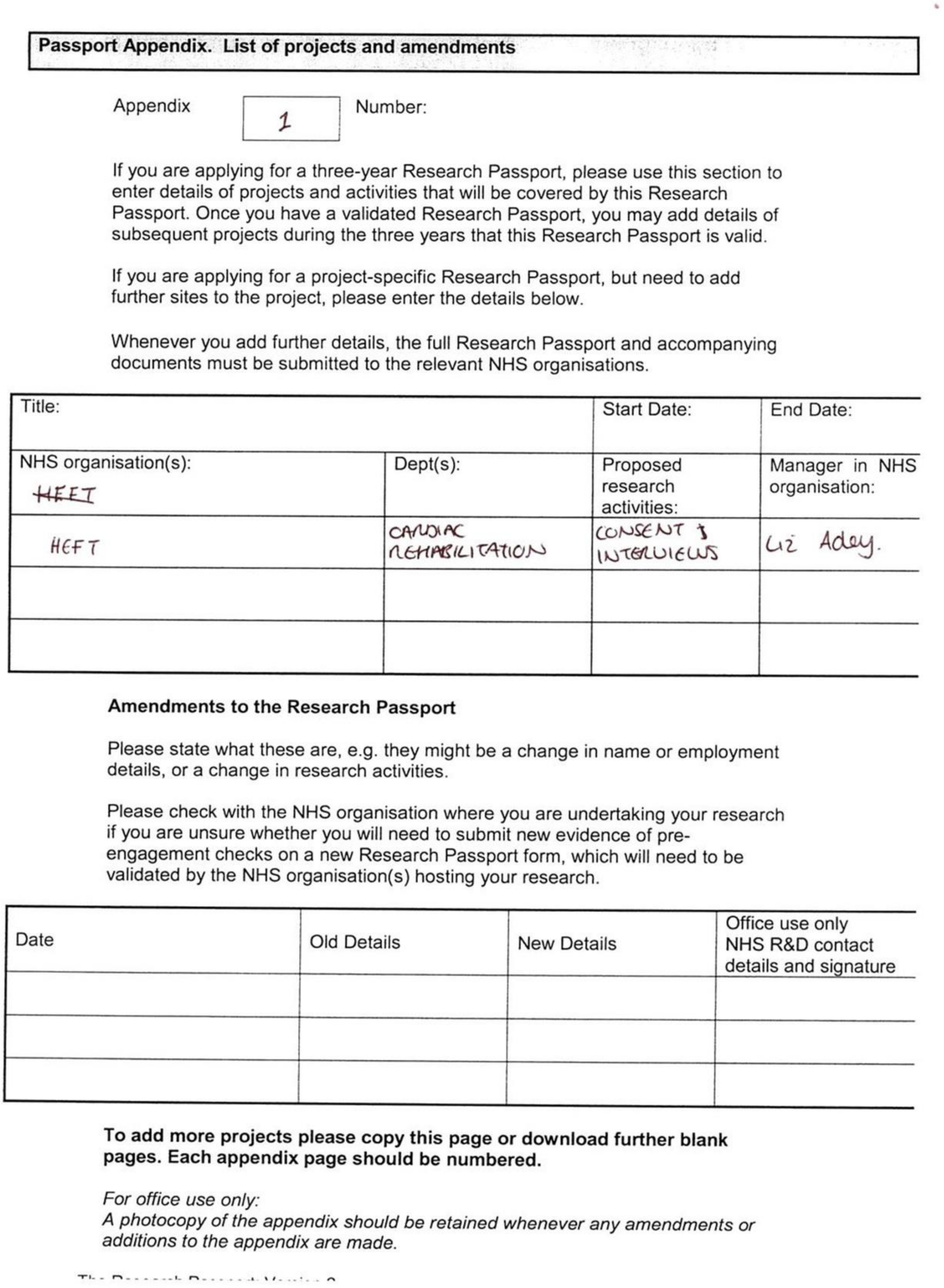
Confirmation of valid Research Passport: Project specific ☐ Three-year ☒ Other End date ☐

Signed:	Jocelyn Bell	Date:	04/04/2012.
Name:	JOCELYN BELL		
NHS Organisation Name and contact details	R&D, ARDEN HOUSE, SANDWELL & WEST BIRMINGHAM HOSPITALS NHS TRUST. CITY HOSPITAL, BIRMINGHAM, B18 7QH 0121 507 4811 jocelyn.bell@nhs.net		

Date ~~Honorary Research Contract~~/letter of access issued *(delete as appropriate)* 05/04/2012



If required, this section should be added to the Research Passport Form and completed by each NHS R&D office receiving the valid Research Passport. The original Research Passport form and documents should be returned to the applicant.			
Has the Research Passport been validated by a Lead NHS organisation and is this validation acceptable to this NHS organisation?			Yes ☐ No ☐
CV reviewed?	Yes ☐ No ☐	Training?	Yes ☐ No ☐
Evidence of qualifications?	Yes ☐ No ☐	Appendix pages reviewed?	Numbers:
Professional Registration details reviewed?	Yes ☐ No ☐ N/A ☐	Occupational health clearance reviewed?	Yes ☐ No ☐ N/A ☐
Criminal record disclosure reviewed?	Yes ☐ No ☐ N/A ☐	Date of disclosure:	CRB Disclosure Certificate No:
For Research Passport applications submitted after 26th July 2010 only: Confirmation that HEI have subscribed their interest in this individual via the ISA on-line monitoring service, (where appropriate) and have agreed to withdraw the individual immediately, should the individual's ISA registration status change **NB ISA registration, where appropriate, is mandatory from November 2010**			Yes ☐ No ☐ N/A ☐
Checked Electronic Staff Record: Yes ☐ No ☐ N/A ☐			
Signed:		Date:	
Name:			
NHS organisation name and contact details			
Date honorary research contract/letter of access issued *(delete as appropriate)*			



Passport Appendix. List of projects and amendments

Appendix Number: 1

If you are applying for a three-year Research Passport, please use this section to enter details of projects and activities that will be covered by this Research Passport. Once you have a validated Research Passport, you may add details of subsequent projects during the three years that this Research Passport is valid.

If you are applying for a project-specific Research Passport, but need to add further sites to the project, please enter the details below.

Whenever you add further details, the full Research Passport and accompanying documents must be submitted to the relevant NHS organisations.

Title:		Start Date:	End Date:
NHS organisation(s): ~~HEFT~~	Dept(s):	Proposed research activities:	Manager in NHS organisation:
HEFT	CARDIAC REHABILITATION	CONSENT & INTERVIEWS	Liz Adey.

Amendments to the Research Passport

Please state what these are, e.g. they might be a change in name or employment details, or a change in research activities.

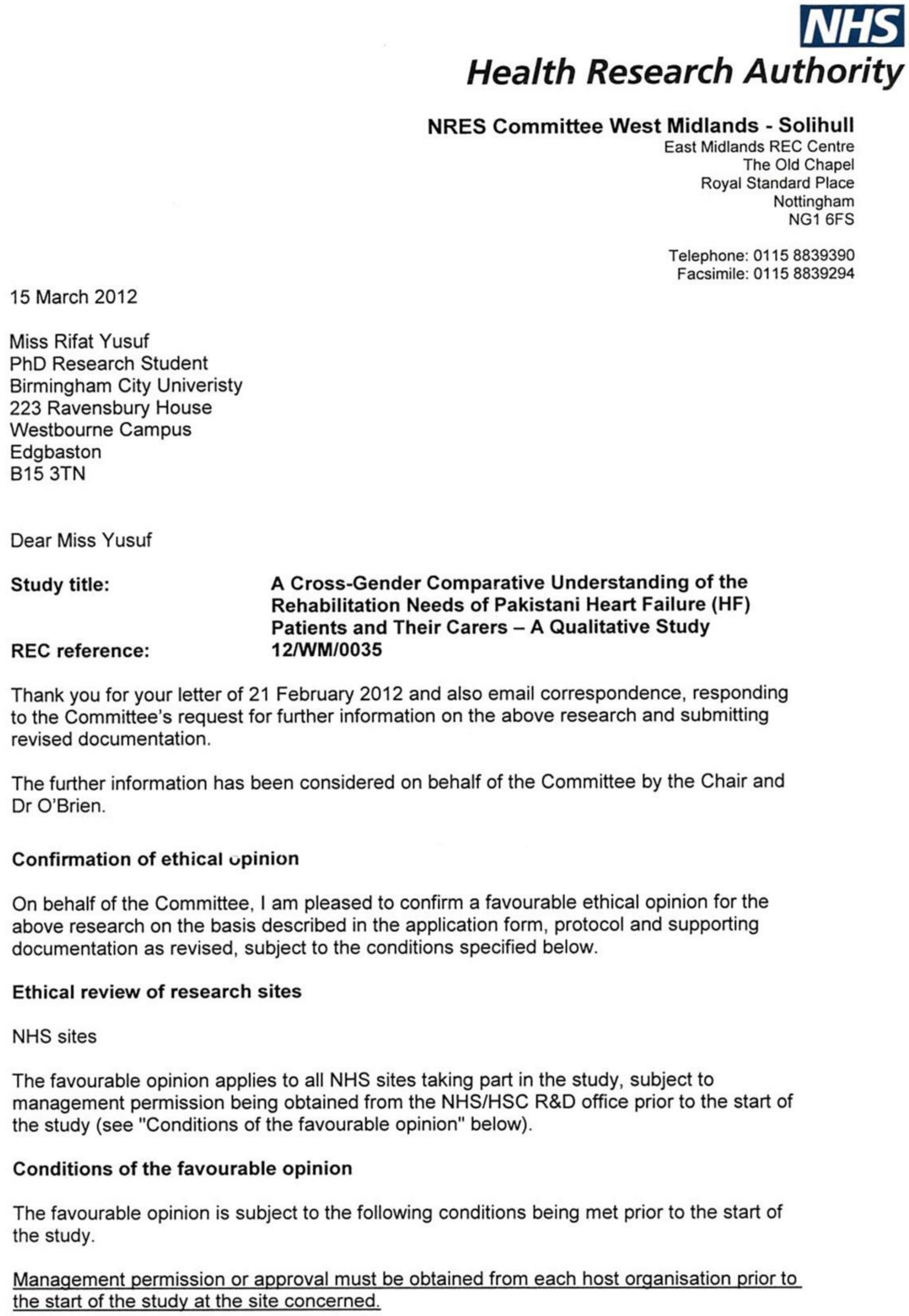
Please check with the NHS organisation where you are undertaking your research if you are unsure whether you will need to submit new evidence of pre-engagement checks on a new Research Passport form, which will need to be validated by the NHS organisation(s) hosting your research.

Date	Old Details	New Details	Office use only NHS R&D contact details and signature

To add more projects please copy this page or download further blank pages. Each appendix page should be numbered.

For office use only:
A photocopy of the appendix should be retained whenever any amendments or additions to the appendix are made.

11.21 RESEARCH ETHICS COMMITTEE APPLICATION (REC)



NHS
Health Research Authority

NRES Committee West Midlands - Solihull
East Midlands REC Centre
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839390
Facsimile: 0115 8839294

15 March 2012

Miss Rifat Yusuf
PhD Research Student
Birmingham City Univeristy
223 Ravensbury House
Westbourne Campus
Edgbaston
B15 3TN

Dear Miss Yusuf

Study title:	**A Cross-Gender Comparative Understanding of the Rehabilitation Needs of Pakistani Heart Failure (HF) Patients and Their Carers – A Qualitative Study**
REC reference:	**12/WM/0035**

Thank you for your letter of 21 February 2012 and also email correspondence, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Dr O'Brien.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of insurance or indemnity		
Interview Schedules/Topic Guides	1.0	03 November 2011
Investigator CV		
Investigator CV		
Letter from Sponsor		04 January 2012
Letter of invitation to participant	1.1 - Patient	21 February 2012
Letter of invitation to participant	1.1 - Healthcare Professional	21 February 2012
Other: CV for Prof E Denny		
Other: CV for Dr S Khan		
Other: CV for J Powell		
Other: Patient Information Letter	1.1	21 February 2012
Other: Information Sheet	1.1	21 February 2012
Other: Interview contact letter	1.1	21 February 2012
Other: Additional patient information	1.0	16 January 2012
Other: Gantt Chart		
Participant Consent Form: Patient	1.1	21 February 2012
Participant Consent Form: Carer	1.1	21 February 2012
Participant Consent Form: Healthcare Professional	1.1	21 February 2012
Participant Consent Form: Carer Consent Form	1.2	13 March 2012
Participant Information Sheet: Patient	1.1	21 February 2012
Participant Information Sheet: Carer	1.1	21 February 2012
Protocol	1.1	21 February 2012
REC application	3.4	17 January 2012
Response to Request for Further Information		21 February 2012

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/WM/0035	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

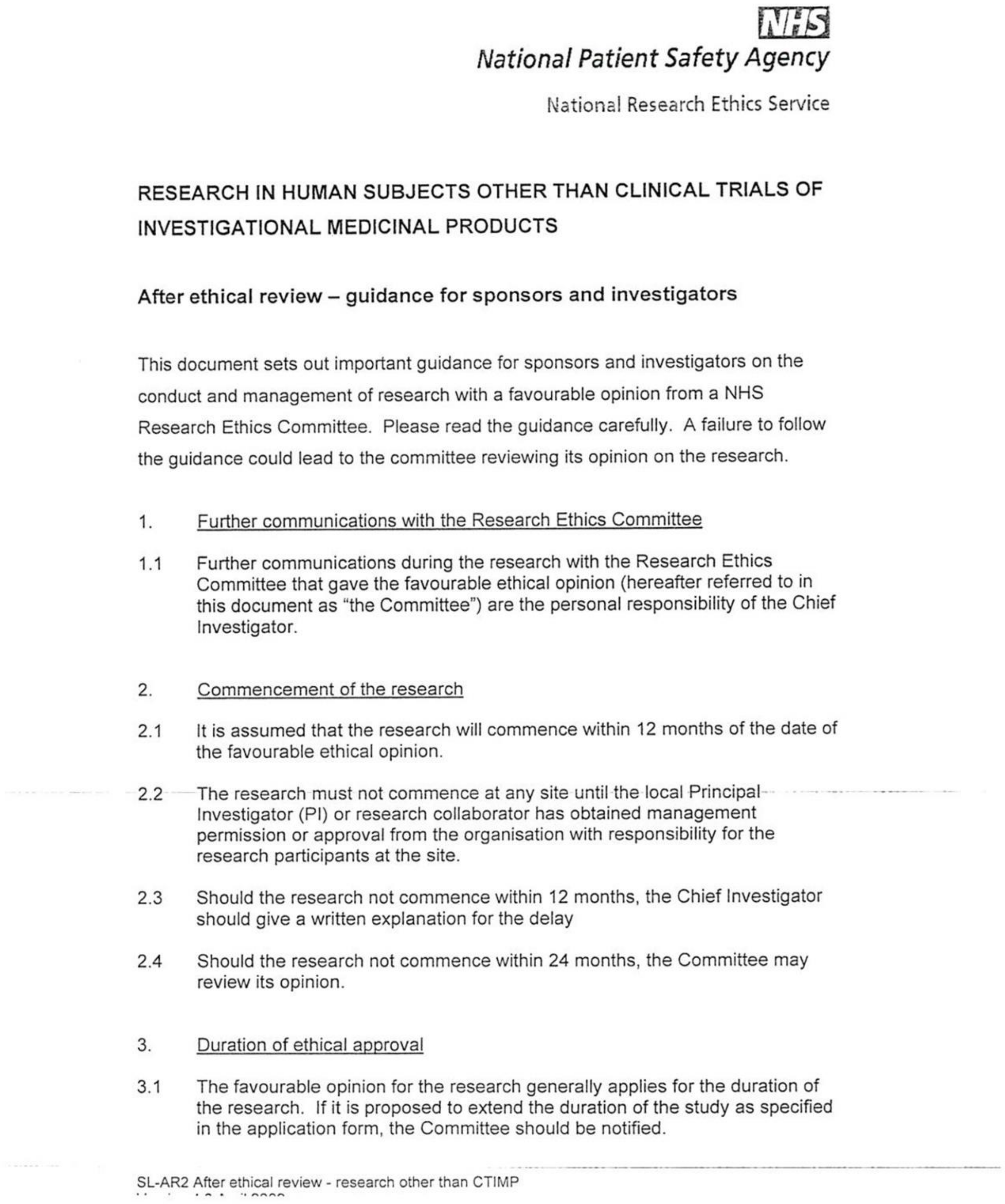
Yours sincerely

P. Wheat

pp **Dr Rex J Polson**
Chair

Email: trish.wheat@nottspct.nhs.uk

Enclosures:	"After ethical review – guidance for researchers"
Copy to:	*Lucy Land, Birmingham City University* *Jocelyn Bell, Sandwell and West Birmingham hospitals NHS Trust*



NHS
National Patient Safety Agency
National Research Ethics Service

RESEARCH IN HUMAN SUBJECTS OTHER THAN CLINICAL TRIALS OF INVESTIGATIONAL MEDICINAL PRODUCTS

After ethical review – guidance for sponsors and investigators

This document sets out important guidance for sponsors and investigators on the conduct and management of research with a favourable opinion from a NHS Research Ethics Committee. Please read the guidance carefully. A failure to follow the guidance could lead to the committee reviewing its opinion on the research.

1. Further communications with the Research Ethics Committee

1.1 Further communications during the research with the Research Ethics Committee that gave the favourable ethical opinion (hereafter referred to in this document as "the Committee") are the personal responsibility of the Chief Investigator.

2. Commencement of the research

2.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

2.2 The research must not commence at any site until the local Principal Investigator (PI) or research collaborator has obtained management permission or approval from the organisation with responsibility for the research participants at the site.

2.3 Should the research not commence within 12 months, the Chief Investigator should give a written explanation for the delay

2.4 Should the research not commence within 24 months, the Committee may review its opinion.

3. Duration of ethical approval

3.1 The favourable opinion for the research generally applies for the duration of the research. If it is proposed to extend the duration of the study as specified in the application form, the Committee should be notified.

3.2 Where the research involves the use of "relevant material" for the purposes of the Human Tissue Act 2004, authority to hold the material under the terms of the ethical approval applies until the end of the period declared in the application and approved by the Committee.

4. Progress reports

4.1 Research Ethics Committees are expected to keep a favourable opinion under review in the light of progress reports and any developments in the study. The Chief Investigator should submit a progress report to the Committee 12 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be in the format prescribed by NRES and published on the website (see www.nres.npsa.nhs.uk/applicants/after-ethical-review/).

4.3 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss the progress of the research.

5. Amendments

5.1 If it is proposed to make a substantial amendment to the research, the Chief Investigator should submit a notice of amendment to the Committee.

5.2 A substantial amendment is any amendment to the terms of the application for ethical review, or to the protocol or other supporting documentation approved by the Committee, that is likely to affect to a significant degree:

(a) the safety or physical or mental integrity of the trial participants
(b) the scientific value of the trial
(c) the conduct or management of the trial.

5.3 Notices of amendment should be in the format prescribed by NRES and published on the website, and should be personally signed by the Chief Investigator. The agreement of the sponsor should be sought before submitting the notice of amendment.

5.4 A substantial amendment should not be implemented until a favourable ethical opinion has been given by the Committee, unless the changes to the research are urgent safety measures (see section 7). The Committee is required to give an opinion within 35 days of the date of receiving a valid notice of amendment.

5.5 Amendments that are not substantial amendments ("minor amendments") may be made at any time and do not need to be notified to the Committee.

6. Changes to sites

Management permission (all studies)

6.1 For all studies, management permission should be obtained from the host organisation where it is proposed to:

- include a new site in the research, not included in the list of proposed research sites in the original REC application
- appoint a new PI or Local Collaborator at a research site
- make any other significant change to the conduct or management of a research site.

In the case of any new NHS site, the Site-Specific Information (SSI) Form should be submitted to the R&D office for review as part of the R&D application.

Site-specific assessment (where required)

6.2 The following guidance applies only to studies requiring site-specific assessment (SSA) as part of ethical review.

6.3 In the case of *NHS/HSC sites*, SSA responsibilities are undertaken on behalf of the REC by the relevant R&D office as part of the research governance review. The Committee's favourable opinion for the study will apply to any new sites and other changes at sites provided that management permission is obtained. There is no need to notify the Committee (or any other REC) about new sites or other changes, or to provide a copy of the SSI Form.

6.4 Changes at *non-NHS sites* require review by the local REC responsible for site-specific assessment (SSA REC). Please submit the SSI Form (or revised SSI Form as appropriate) to the SSA REC together with relevant supporting documentation. The SSA REC will advise the main REC whether it has any objection to the new site/PI or other change. The main REC will notify the Chief Investigator and sponsor of its opinion within a maximum of 35 days from the date on which a valid SSA application has been received by the SSA REC.

Studies not requiring SSA

6.5 For studies designated by the Committee as not requiring SSA, there is no requirement to notify the Committee of the inclusion of new sites or other changes at sites, either for NHS or non-NHS sites. However, management permission should still be obtained from the responsible host organisation (see 6.1 above).

7. Urgent safety measures

7.1 The sponsor or the Chief Investigator, or the local Principal Investigator at a trial site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

7.2 The Committee must be notified within three days that such measures have been taken, the reasons why and the plan for further action.

8. Serious Adverse Events

8.1 A Serious Adverse Event (SAE) is an untoward occurrence that:

- (a) results in death
- (b) is life-threatening
- (c) requires hospitalisation or prolongation of existing hospitalisation
- (d) results in persistent or significant disability or incapacity
- (e) consists of a congenital anomaly or birth defect
- (f) is otherwise considered medically significant by the investigator.

8.2 A SAE occurring to a research participant should be reported to the Committee where in the opinion of the Chief Investigator the event was related to administration of any of the research procedures, and was an unexpected occurrence.

8.3 Reports of SAEs should be provided to the Committee within 15 days of the Chief Investigator becoming aware of the event, in the format prescribed by NRES and published on the website.

8.4 The Chief Investigator may be requested to attend a meeting of the Committee or Sub-Committee to discuss any concerns about the health or safety of research subjects.

8.5 Reports should not be sent to other RECs in the case of multi-site studies.

9. Conclusion or early termination of the research

9.1 The Chief Investigator should notify the Committee in writing that the research has ended within 90 days of its conclusion. The conclusion of the research is defined as the final date or event specified in the protocol, not the completion of data analysis or publication of the results.

9.2 If the research is terminated early, the Chief Investigator should notify the Committee within 15 days of the date of termination. An explanation of the reasons for early termination should be given.

9.3 Reports of conclusion or early termination should be submitted in the form prescribed by NRES and published on the website.

10. Final report

10.1 A summary of the final report on the research should be provided to the Committee within 12 months of the conclusion of the study. This should include information on whether the study achieved its objectives, the main findings, and arrangements for publication or dissemination of the research including any feedback to participants.

11. Review of ethical opinion

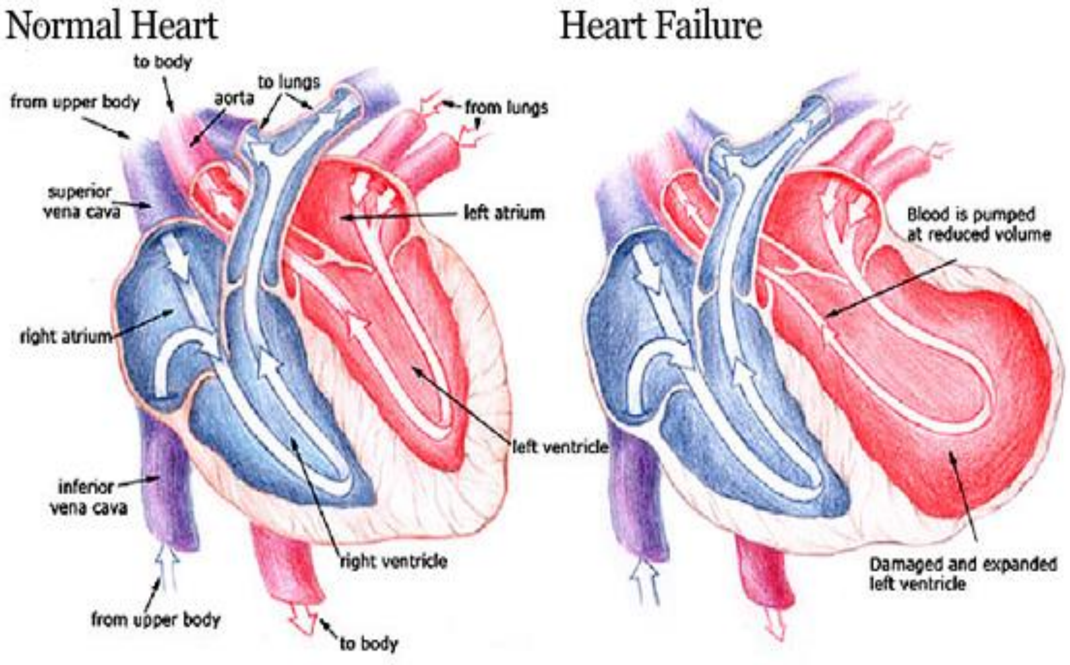
11.1 The Committee may review its opinion at any time in the light of any relevant information it receives.

11.2 The Chief Investigator may at any time request that the Committee reviews its opinion, or seek advice from the Committee on any ethical issue relating to the research.

11.22 HEART MUSCLE DIAGRAM

Heart Muscle (Normal vs. Heart Failure Heart)

The heart is a muscular pump, made up of four chambers. They are the left and right atria and the left and right ventricles. These chambers have to pump regularly and in sequence to ensure an adequate blood moving in the right direction. The pumping action of the four chambers is co-ordinated by the electrical signals telling the heart when to contract and relax. Blood from the legs and arms and organs of the body enters the right side of the heart into the right atrium. It is pumped to the right ventricle and from there the heart pumps the blood to the lungs, where it takes up oxygen and gets rid of the carbon dioxide it has been carrying. This oxygen rich blood then enters the left side of the heart into the left atrium. It is pumped into the biggest muscle, the left ventricle and from there it is pumped into the aorta to all parts of the body including the heart muscle itself.



11.23 HEART FAILURE MEDICINES

Heart Failure Medicines	
Medicines	Description
Diuretics (Amiloride, Bendrofluazide, Bumetanide, Chloralidone, Furosemide, Metolazone, Torasemide).	Diuretics sometimes referred to as 'water tablets' help with getting rid of excess fluid by the process of passing more urine. Furthermore, it helps with the reduction of swelling, relieves shortness of breath, lowers blood pressure and helps other drugs work better that may be prescribed (ACE inhibitors and beta-blockers). Common side-effects are frequent visits to the toilet, dizziness and exacerbation of gout.
ACE inhibitors (Captopril, Cilazapril, Enlapril, Lisinopril, Perindopril, Ramipril, Trandolapril).	ACE inhibitors are prescribed to help lighten the workload of the heart and make it easier for the heart to pump blood around the body. They help the diagnosis of heart failure from worsening and protect re-occurrences of heart attacks from occurring by improving blood flow to the heart muscle. Activity is improved of patient markedly. However, common side-effects are dizziness and irritating cough.
Angiotensin-II receptor antagonist (Candesartan, Irbesartan, Losartan, Valsartan).	These medicines relax the blood vessels allowing the blood to flow more easily reducing the workload of the heart in addition to reducing blood pressure which in turn reduces the risk of having a heart attack. Common side-effects are dizziness, diarrhea and decreases in blood pressure.

Beta-blocker (Atenolol, Bisoprolol, Carvedilol, Metoprolol, Nebivolol, Propranolol).	Beta-blockers help to prevent the heart from beating to quickly and too forcefully. Beta-blockers control the heart rhythm, increase the chances of living longer and increase the amount of blood the heart pumps out. Common side-effects are tiredness, disturbed sleep, cold hands and feet, diarrhoea, impotence and mood swings.
Aldosterone antagonist (eplerenone, Spironolactone).	Aldosterone helps control the potassium levels in the blood and act as a mild diuretic. Side-effects include diarrhoea, reduced kidney function and slightly enlarged and tenderness in breasts for men (feminisation).
Cardiac glycoside (Digoxin)	Digoxin slows down and strengthens the heartbeat controlling irregular heart rhythms and helps the heart pump around the body more efficiently. Common side-effects include nausea and vomiting, diarrhoea or constipation, dizziness, confusion, enlarged breasts in men and a slower or irregular heartbeat.
Antiplatelet (Aspirin, Clopidogrel).	Anti-platelet medicines are usually lifelong which helps to make the blood less ‘sticky’, it reduces the risk of clots forming and reduces the overall risk of having a heart attack or stroke. Common side effects include indigestion, nausea, vomiting.

11.24 CARDIAC REHABILITATION PHASES 1-4

Phase 1

This phase occurs when a person is an inpatient at hospital.

Many issues are considered during this phase. These include reassurance, risk factor assessment and modification, education for the patient and his/her family and discharge planning. A CR nurse will spend time with the patient and their family. This is usually spread over the duration of the hospital stay. The patient will be asked what they think caused their cardiac event and to discover the patient's knowledge base and misconceptions. Also discussed are the disease processes, the patient's individual risk factors, medication, chest pain management and employment. Apart from verbal communication, a video and leaflets are used. If a patient has had a heart attack, the Hear Manual or the hospital's own package will be given.

The Heart Manual is a 12-week rehabilitation programme for patients recovering from a myocardial infarction (MI). It consists of a workbook, in six weekly sections, and includes a phased programme of health education, home based exercises and stress management. A CD is also provided and contains a programme of relaxation exercises, a scripted interview between a doctor and a patient, and a talk by a doctor targeted at the patient's partner or family member. It has been shown, in major clinical trials that patients using the Heart Manual have improved psychological adjustment at one year with fewer readmissions to hospital within the first six months.

Those patients who are not suitable for the Heart Manual, such as patients who are physically unable to exercise or those with severe heart failure, receive the hospital's own package. Families are involved as much as possible. Prior to discharge the patient will be informed when they will be sent for to attend hospital for a cardiology review. He/she will also be informed of the Primary Care staff involvement at home and be given a contact number for the Rehabilitation Team.

Phase 2

This is the early post-discharge phase.

Members of the Primary Care team based in General Practice, who are trained as Heart Manual Facilitators, provide support during this phase. They visit the patient and their family at home on several occasions, reinforce lifestyle risk factors, monitor anxiety and depression levels and generally support the patient and their family. This support continues for approximately three months.

Phase 3

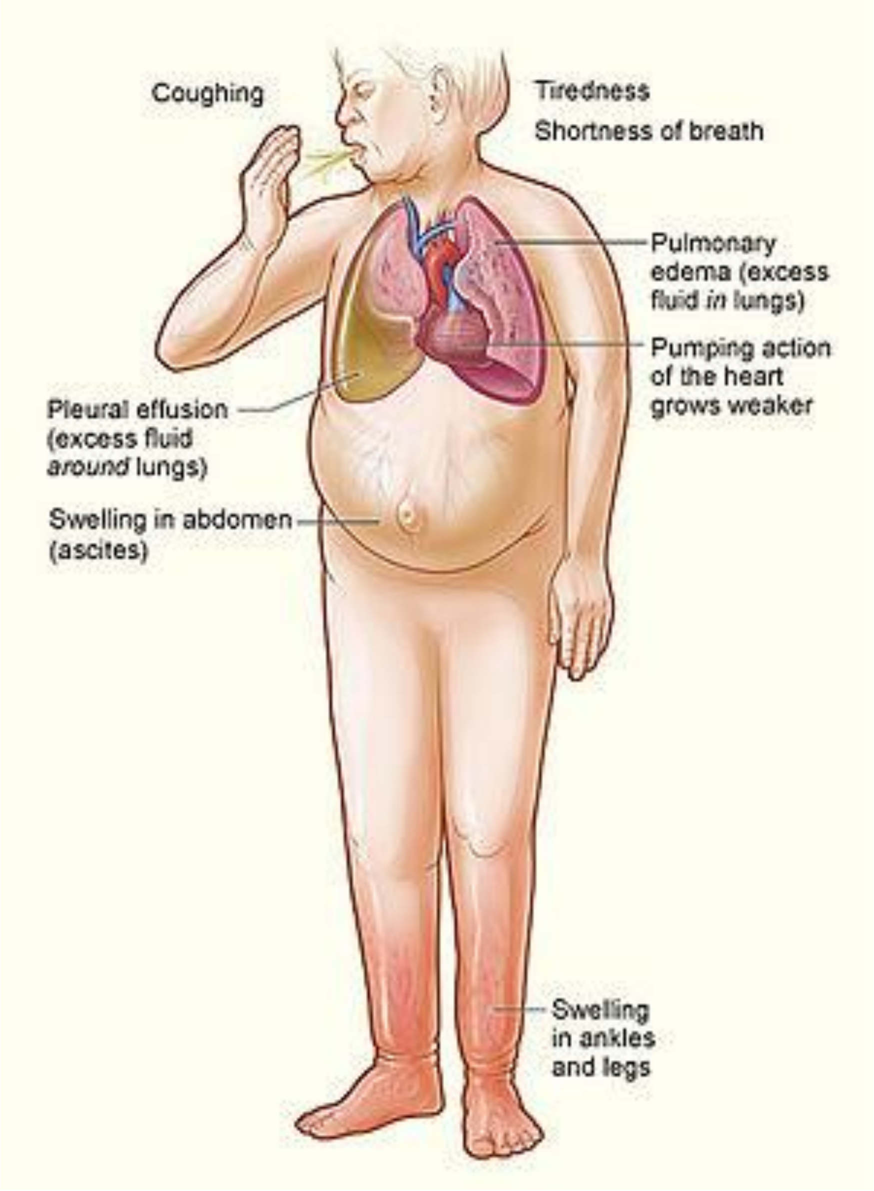
This programme usually starts 6-8 weeks after a heart attack or 12 weeks after cardiac surgery or other intervention and lasts for 12 weeks. However, if the patients need more support then they may remain in phase 3 for longer. Phase 3 takes the form of a structured exercise programme with educational and psychological support, and advice on risk factors.

It is tailored to suit individual needs. The CR nurses co-ordinate the programme and the British Association for Cardiac Rehabilitation (BACR) trained fitness instructors provide the exercise part of the programme.

Phase 4

This phase has two main components. The first is long term maintenance with advice on lifestyle and risk factors, including management of blood pressure, cholesterol, glucose levels and drug therapy. Secondly, a structured exercise programme in conjunction with the local community is run at local community leisure centres. This is to help encourage patients to maintain their new lifestyle changes, improve fitness, and to promote exercise on a regular basis. Phase 4 is co-ordinated by a CR nurse and the exercise part is led by a BACR fitness instructors.

11.25 DIAGRAM OF HEART FAILURE PATIENTS SYMPTOMS



11.26 MAP OF AXIAL CODING

Axial Coding - Medication Management

Phase 1

Category: Medication Management - Adherence Phase 1

Dimension Range - Frequency: Daily

Duration - Once, Twice, Three Times Daily

Intensity - Non-Existent, Mild, Extreme

Adhering - Present vs. Absent (strict/casual)

Causal Condition - Medical Condition, Illness, Reduces Pains of Illness and Co-Morbidities

Phenomenon - Medication Adherence/Management

Intervening condition –
knowledge of Importance of Medicines and Understanding
Using Dossette/Blister Pack
Dislike Taking Medicines
Concerns of Side-Effects (Continuing Pains, Doubtful if Medicines Working)
Support Networks
Alleviates Pains and Controls Symptoms

Intervening strategies - Medical Instruction/Education/Cardiac Rehabilitation

Action Strategies - Blister Pack, GP, Family/Friend Support, Faith, Trust in GP

Consequences - Relief of Pain, Control Illness, Relives Symptoms, Fixed Routine, Blister Pack

12 GLOSSARY OF TERMS AND ABBREVIATIONS

Chronic Heart Failure	CHF	
Category	CATEGORY	
Axial Coding	AXIAL CODING	
New York Heart Classification	NYHA	Class 1-4 (No Symptoms, Symptoms on Moderate Exertion, Symptoms on Mild exertion, Symptoms at Rest)
NVIVO	NVIVO	
Risk Factors	RISK FACTORS	
Chronic Heart Disease	CHD	
South Asians	SOUTH ASIANS	
Community Heart Failure Nurse	CHFN	
Heart Failure Nurse	HFN	
Health Care Professional	HCP	
Focus Groups	FG	
Co-Morbidities	CO-MORBIDITIES	
National Health Service	NHS	
Conceptual Category		
Culture	CULTURE	
Central Category		
Religion	RELIGION	
COPD	CHRONIC OBSTRUCTIVE PULMONARY DISEASE	
Hypertension	HIGH BLOOD PRESSURE	
Open Coding		
Rehabilitation Phases	REHABILITATION PHASES	1-4
LV		
RV		

BHF	BRITISH HEART FOUNDATION	
ECG	ELECTROCARDIPGRAM	Assessment of heart Rhythm
Pace-Maker Electrical Devise		
MI	MYOCARDIAL INFARCTION	
BNP TEST		Blood Test Measuring Level of Certain Hormones Related to heart Failure
Echocardiogram	ECHO	Explores Activity of Valves, Muscles and Pumping Action of Heart In Action
Lung Function Test	LFT	Tests Assessing Lung Function
Ejection Fraction	EF	% of Blood Pumped Out of Left Ventricle Per Heart-Beat
Swelling	Oedema	
Congestive Heart Failure	CHF	Poor Pumping Action of Heart Leading to Build Up of Blood in Lungs and Other Body Parts
Angina	Angina	Pressure Across Chest/Chest Pains
Arrhythmias	Arrhythmias	Abnormal Heart Rhythm
Self-Management	SM	Understanding and Managing Own Condition/Symptoms