

**The psychosexual needs of lesbian women affected by
cancer: A phenomenologically inspired study moving
education and practice forward.**

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Abstract

The past two decades has seen an increased interest in, and awareness of the ways in which cancer and concomitant treatments effects individuals and couples in terms of their expressions of sexuality and sexual health (incorporating psychosexual health) (Sadovsky & Bassoon et al, 2010, Greenwald &McCorkle, 2008, De Vocht, 2011). However, the research studies found focused on the impact on heterosexual individual's and couples, with a dearth of literature pertaining to the impact on lesbian and bisexual women affected by cancer. Although, the health care needs of individuals from sexual minority groups has begun to be recognised and addressed by practitioners (Stonewall, 2010, Davey, 2012), the lack of available literature to help guide practice in this area means that they often fail to recognise the needs of the lesbian women in their care.

The aims of this study were therefore twofold, firstly to explore the sexuality, sexual health (incorporating psychosexual health) and relationship experiences of lesbian and bisexual women who have been diagnosed and received treatment for cancer. Secondly to use the outputs from the first aim, to develop a conceptual framework and model for practitioners working with lesbian and bisexual women in the fields of cancer care in regards to these areas.

This study was designed with a research design which enabled the 'voices' of both the lesbian and bisexual women, and the cancer practitioners to be heard. The overarching research methodology was descriptive phenomenology, however, it became evident that the traditional approach taken in descriptive phenomenological studies (Giorgi, 1985, 2009, Rutherford & McIntyre et al, 2012) would not yield the breadth and depth of data needed to develop the conceptual framework. Therefore, as suggested by Mayoh & Onwegbuzie (2013) the concept of applying the steps that underpin action research throughout the phenomenologically inspired journey were used.

As a starting point for the study, and to assess the readiness and preparation of practitioners in cancer care the views and experiences of both an expert panel and focus groups of specialist practitioners were sought on four occasions. The face to face interactions were supplemented with paper and online questionnaires. A documentary analysis of the United Kingdom (UK) government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education was undertaken to explore the actual practice situation. This was followed by review of undergraduate nursing and medical curriculum with a focus on the holistic assessment and management of sexuality and sexual health needs. In addition, the UK governmental and professional body Lesbian, Gay, Bisexual and Transgender (LGBT) specific directives for good patient care practice, together with the LGBT specific content within undergraduate nursing and medical curriculum were systematically analysed.

The voices of lesbian and bisexual women affected by cancer – both survivors and partners provided a wealth of in-depth information through the individual interviews and online qualitative questionnaires. This gave new insights into and increased understanding of the issues faced by participants. It highlighted similarities and differences with and from the findings from the heterosexual studies, and provided the baseline from which the conceptual framework and model were developed. It was seen as essential that these had a theoretical basis that practitioners could accept and utilise and that it was incremental to recognise the longevity of the support and guidance sought by participants. When shared with practitioners the conceptual framework and model were well received and only minor refinements were needed. It does enable cancer care practitioners to offer more tailored care to the lesbian and bisexual women in their care. Especially in regards to the women's sexuality, sexual health (incorporating psychosexual health) and relationships, and has led to links and work with both Macmillan Cancer Support and Relate the UK's largest provider of relationship support.

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Chapter One

Introduction

“All journeys have secret destinations of which the traveller is unaware” (Buber, 1955 /1995)

This study was developed to meet the needs identified by both lesbian and bisexual women and healthcare practitioners (HCP's) in regards to the impact of cancer on these women's sexuality, sexual health (incorporating their psychosexual health) and relationships. When reviewing the existing evidence base on which professionals can draw, it appeared that whilst there is an evolving body of research, evidence and clinical literature that sheds light on the sexuality, sexual health / psychosexual and relationship consequences of female and reproductive cancers (especially breast cancer) interventions which may aid adaptation and recovery individuals and couples were only found for heterosexual women. In addition, studies were available in respect to the impact on gay men affected by cancer with regards to these areas (Asencio & Blank et al, 2009, Thomas, 2013, Wassersug, 2013). Overall, there appeared to be an apparent dearth of research and literature focussing on these areas when experienced by lesbians, bisexual women, and women partnered women and their partners. Furthermore, despite the increase in both interest in and availability of research on the subject with regards to heterosexual women, the literature suggested that much of the information was not being applied. There still appeared to be some way to go before the majority of nurses and other health care professionals (HCP's) felt comfortable and confident enough to offer skilled and appropriate sexuality, sexual and psychosexual health focused care to their patients per se (Schmitz and Finkelstein, 2010). Sexuality is seen as central to being human (Poorman, 1982) and as such, failure to address this important aspect of humanity in practice can be viewed as dehumanising and unacceptable. Therefore, the study had at its heart the need to explore how this aspect of humanness was being experienced by lesbian and bisexual women, effected by cancer and treatments, together with the preparedness of cancer care practitioners to address this area within their practice. This perspective supported assessment of the perceived, and in some areas the unrecognised educational needs of the practitioners, as well as the experiences and needs of the women and their partners. This in turn facilitated the development of a conceptual framework and educational model to empower practitioners to provide sensitive and appropriate care for the patients within their sphere of practice.

Fish & Anthony (2005) and Fish (2010) are examples of the limited research found that had been undertaken with lesbian and bisexual women with breast cancer. These explored the impact of the cancer on the women's lives in general and their experiences of health care practitioners, but did not however explore the effects on the women's sexuality, sexual

health/psychosexual health and relationships. It was clear to me that as a nurse, psychosexual and relationship therapist, senior healthcare educationalist (with a sexual health specialism), senior healthcare educational manager and researcher that I was ideally placed to undertake a study to develop of a conceptual framework and model from which recommendations for policy, practice and practice education could be made. Ultimately these could provide much needed guidance, together with making recommendations for policy and practice. Furthermore, as a lesbian woman I felt it appropriate to carry out this study using a methodology that would 'give a voice to the lived experience' of this marginalised and often hidden group of women. Therefore, it was important that the methodological underpinning of the study should allow the voices of these women to be 'brought forward' and placed at the centre of the study. To that end a descriptive phenomenological approach was seen to be the most appropriate for this study (see Chapter Two). The advantage of this approach is that it describes without the researcher prioritising and interpreting is within praxis. Thus, the rich detailed storied given by the women could be seen without judgment (Finlay, 2011). However, it quickly became apparent that the traditional approach taken in descriptive phenomenological studies (Giorgi, 1985, 2009, Rutherford & McIntyre et al, 2012) would not yield the breadth and depth of data needed to develop the conceptual framework. Nevertheless, until the study started, the complexity of the task being undertaken had not been fully anticipated. As it progressed, it became more obvious that different methods of data collection would be needed regarding both the literature and each of the groups concerned. Descriptive phenomenology challenges and invites us to look again at human experience, our place in the world and how we interact with others (Finlay, 2010). Using this definition accepts the possibility of the use of additional methods such as observation to support and underpin phenomenological study. However, to remain true to the principles of phenomenology great care had to be used to identify the additional methods used and to consider how they interlinked and/or related to one another (Van Manen, 2013). As this study involved new developments and changes in practice, a logical way to link the different planned activities (as they needed to be used in appropriate sequences) the decision was made to review how other researchers had addressed this concern. Van Manen (1990, 2013), Finlay (2009a) and Mayoh & Onwugbuzie (2013) all point out that they too had found it necessary to see how other methods could be modified and adapted to fit within the phenomenological paradigm. Thus, the decision was made to accept their viewpoint of a phenomenological journey, with the findings and reports (in this case the dissertation) illustrating how the philosophical principles of phenomenology underpinned the whole research process. To this end, the study was in Finlay's (2009a) terms, inspired by phenomenology rather than a true phenomenological study.

As an educationalist and practitioner familiar with research designed to change practice, the concept of action research appeared to offer a structure through which the various data sets could be collected and collated within a format that would facilitate the development of a conceptual framework and model for practice. The adoption of an action research approach within a phenomenological study was supported by, and indeed, advocated for by Mayoh & Onwegbuzie (2013), who believe that approaches such as action research can be used to draw on the phenomenological philosophy without prejudicing the phenomenological method. Accepting their perspective facilitated the use of the differing methods **within** the philosophical framework in which the study was based. Therefore, it was seen as appropriate to utilise as exemplars, the steps of action research through the phenomenologically inspired journey (see Chapter two).

As a nurse, therapist and researcher this presented ethical and professional challenges, especially in respect of the duty of care a central tenet in professional practice. If a participant displayed or disclosed personal distress and difficulty, the role and boundary constraints of being a phenomenological researcher could potentially be at odds with the professional codes of practice of both the Nursing & Midwifery Council (NMC) and the College of Sexual & Relationship Therapists (COSRT) (COSRT, 2015, NMC, 2015). Hence a way forward needed to be found that would marry these various roles together, whilst maintaining both researcher and professional integrity.

Positionality Statement:

Derry (2017) suggests that it is important that a researcher states their positionality, relative to their research orientation and study, to reduce the impact of bias and hidden personal constructs on the research and thereby to maximise the validity of the study. She further argues that power dynamics are present in every aspect of the research process and it is the ethical responsibility of the researcher to intentionally and mindfully attend to their role(s) in the contextual power interplay of the research process. Therefore, I have outlined my positionality at the outset of the study, and return to it through all phases of the study, illustrating this by the use of reflexive comments. For ease of location and reading these positionality statements and actions will be highlighted by a blue background throughout the document.

I am a white, lesbian, cisgender woman, I have lived in the U.K. all my life. I come from a working class background (with my brother being the first in the family to attend university), I started my nursing career in 1979 and subsequently moved into nurse education in 1986 at

which point I began my post basic education, firstly at diploma level, moving onto undergraduate and postgraduate studies. Within nursing/healthcare education I progressed into a senior academic management role, whilst maintaining my teaching commitment and focus.

Throughout, my subject specialist area has been sexual and psychosexual health. In pursuance of this, I became a psychosexual and relationship therapist in 1997 which aided me in my subject specialist area and broadened my practice base and skills. Together with many of my lesbian and gay friends, I have lived through the 'AIDS' crisis, sadly losing some friends along the way. My interest in the psychosexual aspects of patient care was borne of my experience whilst working clinically with the 'first generation' of Human Immunodeficiency Virus (HIV) / Acquired Immunodeficiency Syndrome (AIDS) patients back in 1984. At this time I was horrified by the frank prejudice of staff and their unwillingness at times to care for these vulnerable people and their significant others. I 'came out' to my parents and close friends in 1986, and in that era, was fortunate that during this process I did not experience negative responses.

I have lived through times of huge change in terms of LGBT rights, from times of open homophobia and the 'need' to remain hidden, to an era of greater openness and recognition of the equality of LGBT individuals and relationships, being politically active within LGBT voluntary organisations and therefore part of this movement for change. During this time I have supported many people as they 'came to terms' with their sexuality and have worked with people who were victims of homophobic 'hate crime'. Although I am a lesbian, I am conscious that I do not share the same experiences of either older lesbians, who would potentially have experienced greater prejudice, and lifestyle restrictions than myself, or those of the younger generations of lesbian, who are potentially able to 'enjoy' greater freedoms than their older predecessors.

During my career as a healthcare educator I have been witness to the (on the whole) changing attitudes of practitioners towards LGBT patients for whom they are caring. Together with greater awareness and openness of some staff, to the need to address with patients, the potential impact of ill health on their sexual function. However, through my experience of facilitating 'moving forward' with breast cancer sessions with women with breast cancer, regarding the impact of breast cancer on the female participants sexuality, relationships and intimacy, it has become apparent that these are areas seldom mentioned or addressed by health care staff in practice.

As both a nurse and therapist my practice has always been based on a person centred philosophy /approach - with a focus on individualised, compassionate, holistic care /practice.

This philosophy has also underpinned my education practice. My pedagogy was and is, student centred, with a focus on the growth and development of individuals building upon their existing knowledge and experience, whilst taking actively account of their individual backgrounds, learning styles and histories. My focus throughout my career as nurse, therapist and educator has been on providing high quality care to patients /clients and their significant others. This has meant always striving for the provision of excellent care, either directly as a practitioner or vicariously as an educator. My personal spiritual beliefs reflect these person – centred qualities, as a Buddhist these are core beliefs, while, a further Buddhist belief is that there is no ‘one reality’, each person experiencing the world differently - that is ‘their reality’. Each of these elements have shaped my research decisions, practices, approaches, epistemologies, and agendas. It is therefore essential that I am conscious of my own biases, values and experiences and wish to make these explicit within this research thesis, through positionality prose, reflexive comments and critical reflection.

It was recognised from the outset, that within qualitative research the role of the researcher regarding the ethical issues of power, control and empathetic understanding are central to the co-production of the tentative ‘data’ and thus integral to this study. This was seen as a key concern when addressing the reality of the sensitive issues which could be potentially brought forward by participants. In studies such as this one sexuality, intimacy and relationships are so emotionally invested by, and very private to individuals. Therefore these needed to be sensitively addressed and managed, something for which I had the required expertise and experience.

The Aims Of This Research Study Were Therefore:

- To explore the sexuality, sexual health (incorporating psychosexual health) and relationship experiences of lesbian and bisexual women who have been diagnosed and received treatment for reproductive and female cancer.
- To develop a conceptual framework for practitioners working with lesbian and bisexual women in the fields of cancer care in regards to their sexuality, sexual health (incorporating psychosexual health) and relationships.
- To make recommendations for policy, practice and professional education to enhance the quality of care and hence quality of life of this marginalised group

Due to the nature of qualitative research it is axiomatic that fixed objectives are constricting to the nature of interpretive enquiry, therefore for each specific aspect of the study specific aims or key questions were developed at the time in which data was collected. As mentioned

previously, at the outset of this phenomenologically inspired journey the complexity of the task being undertaken had not been fully anticipated. Having decided to use the concept of action research to facilitate the study, a way had to be found to illustrate how this fitted within the phenomenological principles being used for the study as a whole. As this study involved new developments and changes in practice, the links between the different planned activities and the appropriate sequences are given as a map of the overall study in Figure 1 below. In keeping with both phenomenological research and therapy practice, elements of reflexivity used on the journey have been included as appropriate.

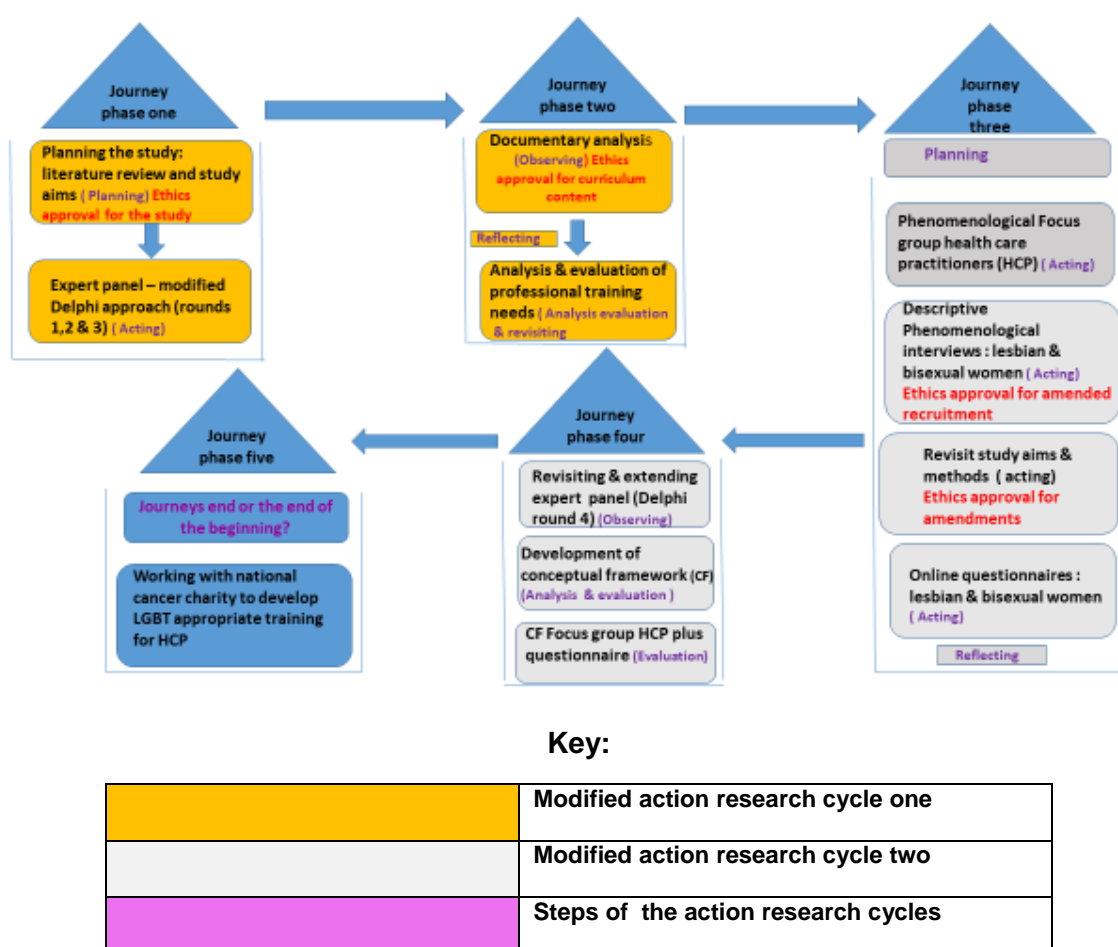


Figure 1: The map of the research journey

In this study each chapter describes a separate phase of the complex research journey undertaken, as the overview /summary below indicates.

Chapter Two: Journey phase one (A) - Developing the phenomenologically inspired journey

The chapter outlines the rationale for the choice of research methodology for the study. Including an exploration of the underpinning epistemological and ontological perspectives, together with the positionality which needed to be considered throughout the study.

Chapter Three: Journey phase one (B) - The starting point

In order to set the scene for the study the chapter addresses the context, including the place of sexuality and sexual health (incorporating psychosexual health) in healthcare and cancer care practice. The importance of incorporating sexuality and sexual health assessment and interventions into cancer care. Societal perceptions and attitudes towards homosexuality in the UK and healthcare professional's attitudes to LGBT patients are also outlined

It includes an overview of cancers in women, the impact of cancer and /or treatment on women's sexuality, sexual health and intimate relationships, gynaecological cancers and breast cancer. Due to the nature of the study, the cancer context for lesbian and bisexual women, incorporates lesbian and bisexual women specific literature review (including lesbian comparative group studies)

Chapter Four: Journey phase one (C) - The expert panel: Workshop and questionnaire

In the absence of information identified in the previous chapters there was a need to seek the views of experts in cancer care and cancer education. The chapter outlines the initial expert panel workshop and questionnaire, together with the findings from these. These provided further emphasis for the urgent need to undertake this study. Furthermore there was a growing concern that in addition to the development of a conceptual framework, there was a need to develop an educational programme or toolkit to address the shortfall in the practitioners comfort and confidence in assessing and addressing their sexuality, sexual health and relationship needs. The findings from the initial expert panel identified the need for the documentary review outlined in chapter five.

Chapter Five: Journey phase two (A) - Documentary review

The chapter outlines the search strategy employed and the documentary review undertaken to explore the UK government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education. A review of undergraduate nursing and medical curriculum with regards to the holistic assessment and management of sexuality and sexual health. Finally the governmental and professional body LGBT specific directives for good patient care practice, together with the LGBT specific content within undergraduate nursing and medical curriculum.

Chapter Six: Journey phase three (A) - Seeking to hear and listening to the voices of the lesbian and bisexual women and their partners: A phenomenological exploration

This chapter outlines the research approach employed with the lesbian and bisexual women effected by cancer. It includes the sampling frame and recruitment of the women diagnosed with cancer and partners. The methods used, were namely face to face interviews and an online questionnaire, data analysis and findings for both the survivors and partners.

Chapter Seven: Journey phase three (B) - Phenomenological focus group with cancer clinical nurse specialists

In addition to the insights and practices of the expert panel, it was seen as essential for the development of a practice facing conceptual framework to elicit the experiences and educational requirements of practitioners working at different levels of practice than those represented by the expert panel. The views and experiences of specialist cancer care nursing practitioners were sort via a focus group. The chapter outlines both the research approach taken together with the findings from the focus group.

Chapter Eight: Journey phase three (C) - Revisiting the expert panel: Delphi round four

In keeping with the modified Delphi method the expert panel were revisited at this point in the research journey to discuss and seek confirmation and further clarification of the findings from the original workshop and questionnaire. The findings from this second expert panel have been presented and discussed within the chapter.

Chapter Nine: Journey phase four (A) - The conceptual framework

Having sought the views and experiences of both lesbian and bisexual women and partners and healthcare professionals in the field of cancer care the next phase of the journey was the development of the conceptual framework arising from the study findings. This chapter outlines both the development and structure of the conceptual framework.

Chapter Ten: Journey phase four (B) - Presenting and discussing the conceptual framework with the cancer specialist nurses

The conceptual framework was presented and discussed with a second group of 18 cancer specialist nurses undertaking the specialist cancer post registration programme at a UK University. The chapter outlines the research approach taken along with the findings from the focus group and questionnaire.

Chapter Eleven: Journey phase five - Journeys end or the end of the beginning? Critique, conclusions and recommendations

This final section includes the critique, conclusions and recommendations. Having outlined the phases of the phenomenologically inspired journey, this chapter reflects on the journey undertaken, including the advantages and limitations of the study, and a review of methodological rigour and positionality. It is both a journey's end and the beginning of a new adventure as highlighted through the personal reflections of the PhD experience and journey. The conclusions also revisit the study aims, with the recommendations being presented.

Chapter Two: Journey Phase One (A) - Developing the Phenomenologically Inspired Journey

To meet the aims of this study, it was essential to gain greater insight into the experiences of lesbian and bisexual women who have had female and reproductive cancers (and their treatments). Information also needed to be gathered regarding their sexuality and sexual health (incorporating psychosexual health). The methodology chosen had to reflect both the aims of the research and enable the women's voices to be in the foreground, with descriptions of their experiences not distorted by subjective interpretation by the researcher. The methodological approaches considered for this study have been discussed and described as has the rationale and justification of the paradigm chosen.

The Over-arching Research Methodology

Study of research documentation reveals that the majority of earlier literature was located within the positivist paradigm, utilising quantifiable, 'objective measures' to assess the impact on the primarily physical dimensions of lesbian and bisexual women's sexuality and sexual health (Boehmer, Potter & Bowen, 2009, Boehmer, et al, 2011, Boehmer et al, 2012 Boehmer, et al, 2014). The positivist approach is based on the existence of an objective reality which can be examined by the application of methods used to 'measure' the reality in the natural sciences. However, a disadvantage of the positivist paradigm is that it is based on an acceptance of the existence of an objective reality, independent of human observation, with the researcher placing themselves outside of the study and remaining value neutral, with the utilisation of standardised protocols aiming for quantification (Finlay, 2002, 2009, 2011). This was clearly not suitable as it did not offer the researcher the opportunity for interaction with or probing the experiences of the study participants.

Crotty (1998) and Denzin & Lincoln (2011) argue social and /or personal events or experiences can only be adequately understood if they are seen in context, including those which are culturally and historically derived. Additionally, as Finlay (2011) argues therapists and other practitioners know intuitively that some things simply cannot be sensibly measured or quantified, the interests of practitioners go beyond simplistic behavioural measures and evaluations. Given the nature of the study, with the cultural and historical background and position of the participants being marginalisation, stigmatisation and cultural denial, the approach chosen needed to recognise the strength of the impact of these aspects of society on the participating women. It also needed to emphasise processes and meanings, and be

concerned with providing a description of how individuals see and experience their world that can be interpreted within the praxis of different professional groups. An interpretivist approach which places emphasis on the social actions and interactions which construct an individual's perceptions of reality, together with the gathering of rich descriptions of the phenomenon of interest was seen to offer an appropriate methodological framework for exploring the lived reality of the participants and gaining insights into their perspectives of their experiences.

Thus, the choice was for a qualitative approach, as it would help address the limited information or insight into the key concerns that impact on the lives of lesbian and bisexual women of the cancer journey, and also support redressing the apparent omissions in knowledge that HCP's have regarding this group. Various different qualitative methodologies were considered for this study. For consistency across the study, it was decided that the approach chosen would be used in all qualitative data collection and analysis, including any interviews and /or focus groups held with health professionals.

Firstly, it could be argued, given that the study would be focussing on the experiences of lesbian and bisexual women, that queer theory would be epistemologically appropriate. However, queer theory with its origins in feminist /women's studies and lesbian and gay studies is defined as exploring the categorisation of sexuality and gender. It further seeks to destabilise these existing identity categories (Green, 2002, Marinucci, 2010). This project did not seek to challenge the notions of the women's self-identified sexual orientation or identity. Furthermore, queer theory questions and challenges the concepts of normal and deviant in relationship to sexuality and gender, being actively concerned with political activism around the concepts of 'normality' (Morland & Willox, 2004). This study, whilst recognising that the notion of sexual 'normality' and the potential effects of homophobia are bound to the 'hidden' nature of the women's relationships and the potential moral judgements of the health care professionals, it does not have political and academic activism at its heart. Rather, it is concerned with giving voice to the women concerned in order to inform health care practitioners for future practice. Indeed it has been argued that queer theory ignores the social and institutional conditions within which lesbian and gay people live (Green, 2002). It is these realities within which the women in this study live and have to learn to negotiate on a day to day level, and importantly, in their dealings with health care practitioners during their cancer journey.

Secondly, as the study would be focussing on the experiences of a marginalised group of women it could be argued that feminist methodology would be appropriate. Feminist research is passionate, political and personal, central to which is the idea of situated knowledge (Kralik & Van Hoon, 2008). There are unifying factors in all feminist approaches, including the valuing

of women's experiences, and the concept of egalitarianism (equality of the power dynamics within the research process). There is a recognition that women are oppressed, that the reasons for the oppression need to be examined and action taken for change. Consciousness raising is used to identify alternative views of the world from a woman's perspective and to empower women /participants (Speedy, 1991, Webb, 1993, Maynard & Purvis, 1994, Purwar, 1997). In part this study fulfilled the criteria for a feminist research study, in so much as it addressed the needs of an under represented, marginalised and oppressed group of women, giving voice and bringing forward their experiences and concerns (De Vault & Gross, 2006). Of central importance, given the dilemma of researcher, therapist and nurse was the equality of the power dynamics within the research experience. This was particularly important throughout the interview and post interview processes. Strategies for the development of mutual trust, facilitation, strategic disclosure, reciprocation and reflexivity were utilised in all contacts with the participants (Reinharz, 1992, Wolfe, 1996) Hesse - Biber, 2011). Also, as with previous phenomenological studies (Notter & Burnard, 2006, Howard Hunt, 2013) the decision was made to utilise feminist research techniques within the principles of phenomenology to maximise the support and enhance the interactions between researcher and participant. However, overall, this study did not however fulfil all of the principles and criteria of a feminist research study as identified above - principally it did and does not directly empower the women participating, although it does indirectly empower them via the knowledge generated and guidance for practice with marginalised women in the future.

A further qualitative methodology considered and explored was grounded theory (Glaser & Strauss, 1967/1999). Deriving from symbolic interactionism which proposes that meaning is understood and negotiated through exchange with people in social processes. The data provides an explanatory theory of the social processes at play in the environment studied. The central belief of grounded theory is that theory is discovered by examining concepts grounded in the data (Charmaz & Bryant, 2010, Charmaz, 2014) However, the purpose of grounded theory is not to tell the participants stories, but to identify and explain conceptually an ongoing activity, seeking to resolve an important concern. Essentially the 'findings' of a grounded theory study are not about the participants, but about the patterns of activity or behaviour in which they engage (Starkes & Brown Trinidad, 2007). The main concern conceptualised in grounded theory may not have been voiced explicitly by participants, but instead abstracted from the data within the context of the research (Glaser, 1998). These were seen to be at odds with the purpose of giving voice to the lesbian and bisexual women therefore grounded theory was not seen as an appropriate methodology for this study.

In contrast to other qualitative research methodologies such as grounded theory (Creswell, 2007), phenomenology does not seek to categorise behaviour or generate theory. As Finlay

(2011) argues phenomenologists do not seek to understand the person by 'inquiring about a subjective inner realm'. Rather, understanding comes from asking 'how the person's world is lived and experienced', and that reality is understood through embodied experience. The truth of an event, as an abstract entity is subjective and knowable only through 'embodied' perception, with the lived body as embodied consciousness (Husserl, 1931; Finlay, 2011).

Therefore from the different choices available it was decided the adoption of a phenomenological approach was the most appropriate for this study, as it aimed to explore the lived experiences of the women. Phenomenology is classically divided into two further different methodologies and their incumbent methods, namely descriptive and hermeneutic/interpretive phenomenology (Husserl, 1931, Heidegger, 1962 / 2010). Whilst both have a fundamental starting point, that is the aim to develop a greater understanding of individuals' experiences through the consciousness of the experienter (Giorgi, 2009), they differ in their philosophical views and research methods. Descriptive phenomenology being primarily focussed on description, whilst hermeneutic phenomenology focusses more on understanding (through interpretation). Husserl's philosophical stance is epistemological, focussed on the nature of knowledge, whilst Heidegger's perspective is ontological, concerned with the nature of consciousness and existence. Thus, phenomenology offers an exploration of experiences - 'givens' - those things brought into an individual's consciousness. Within hermeneutic phenomenology the researcher brings a perspective to the 'given' from theory, analysed using questioning and interpretation of the experience based on previous or known theories or conceptual frameworks (Van Manen, 2014). When applied to this study, this would include theories and models from within the psychology, psychotherapy and psychosexual fields. For a therapist, it would be possible to interpret what the participants said, building up a theory of internal processes and from this extrapolate their world view. On reflection this was seen as taking the focus of the research away from the women's experiences, lessening the 'volume' of their voices.

Therefore, the choice of a descriptive phenomenological (Husserl, 1931, Giorgi, 1997) approach was taken, in order 'see' the world of the women through their eyes and to give voice to them without imposing the researcher's interpretations on their words. This method does not prioritise one issue above another, again reducing the possibility of researcher bias affecting the presentation of the findings, with interpretation within the praxis of the reader. Thus the emphasis remained on the process of analysis describing the women's perceptions of their experiences within the context of both their lives and the cancer journey.

Descriptive philosophy is identified as having an identity and contextual independence related to thoughts, feelings and intentions (Husserl 1931). These serve as a medium of reference to

life's events, people and places, and support in depth study which includes ambiguities and complexities that are based within the evidence collected (Giorgi, 1992). The advantage of the use of descriptive phenomenology, with its philosophy of seeking to understand the 'lived' experience of the informant is that it helps construct specific and detailed experiences of the individual without any ranking of experiences or descriptions. The aim is to gain insights to the lived experience for a specific group, not to generalise to the whole population (Silverman, 2011). This approach is subjective, with data and analysis having a strong reliance on text and all findings being time and place specific. It can provide clarification of social phenomena and enhances the study of reality through inductive processes, which base findings on identifying new concepts rather than relying on deduction from existing theory (Silverman, 2011). However a criticism of this approach is that the subjectivity offers a narrow perspective of reality with a lack of reliability, the data being text based and there is interaction between researcher and participant (Creswell, 2007). Nevertheless, as this study was designed for a specific group, the narrow perspective was seen as strength in order to gain the information needed interaction between researcher and participant was seen as essential.

Phenomenology also offers the researcher the opportunity to slow down, focus upon and dwell with the specific qualities of the lived world of the participant and their world as they experience it, which is the focus of the investigation. In contrast to other research methodologies such as grounded theory (Creswell, 2007) phenomenology does not seek to categorise behaviour or to generate theory. Instead it seeks to give weight to everyday experiences, providing insight and understanding of the human condition, thus evoking what is to be human. This is seen to be congruent with my practice as a therapist, where I focus on the lived experiences of my clients in order to make sense of the situation they are presenting, by 'entering their world'

Husserl (1931) expounded a process that reflects the visceral /embodied texture of experience, the sensual experiencing of life, as it is 'given' to the 'experiencer' with multiple layers of implicit meaning. This way of knowing is seen as integral to both therapy and the building of the therapeutic relationship. In addition, it is argued that phenomenology fits easily with the professional values and skills of therapy - and by extension those of holistic nursing practice (Crotty, 1998). All three areas; phenomenological research, therapy and nursing involve a journey of evolving self - other (I and Thou) understanding and growth, involving similar skills of analytical and inferential thinking, reflexive intuitive understanding, bodily awareness and a capacity for compassion, warmth, openness and empathic understanding (Nelson - Jones, 2002, Osborn, Wraa & Watson et al, 2013).

Phenomenological research recognises that the researcher has a central role in the co-construction of tentative data and is further required to explore these dynamics reflexively.

Again, this is seen to resonate with the dynamics of the therapeutic relationship and centrality of reflexivity in professional therapeutic practice. The processes of co - construction are seen to be potentially transformative for both researcher and participant, offering the participants the opportunity to be 'witnessed' and allows them to 'give voice' to what they are experiencing or have experienced. Opening up new possibilities for both researcher and researched to make sense of the experiences in focus (Levesque - Lopman, 2000, Finlay, 2009. 2011). This was seen to be extremely important for the women in this study as they 'come to terms' with their new reality as women who have had cancer (WWHHC) who also belong to a marginalised and hidden group within society. It cannot be assumed that their experiences of their cancer 'journey' are the same as their heterosexual counterparts. This study has the potential to inform professionals working with the women of their experiences and as a result help to guide appropriate practice.

A key element of descriptive phenomenology is bracketing (Husserl, 1931), however, it is now recognised that the original concept of bracketing, as espoused by Husserl (1931) is not realistic or feasible (Le Vasseur, 2003, Hamill & Sinclair, 2010, Tufford & Newman, 2010), awareness of researcher based factors that can affect a study can help to minimise and reduce bias (Finlay, 2002, Bryman, 2012). Therefore, a self-assessment process based on bracketing (Giorgi, 1985) was used to identify research bias and perceptions prior to and during the study (positionality).

Utilising the concept of action research within a phenomenologically inspired study

One of the aims of this study was the development of a new conceptual framework and model to guide cancer healthcare practitioners when working with lesbian and bisexual women in relation to their sexuality, sexual health and relationships. The necessary stages were planned using Mayoh & Onwegbuzie (2013) argument that action research draws on the phenomenological philosophy and the associated interpretive paradigm without being a phenomenological method. Looking closely at the steps of action research in the light of Mayoh & Onwegbuzie's (2013) premise, it was decided that these would facilitate this phenomenologically inspired study, consequently they were considered in more detail. An action research project proceeds through a spiral of cycles of planning, acting, observing and reflecting, with each of these activities being systematically and self-critically implemented and interrelated. It uses different methods of observation, reflection and planned interventions to make changes in practice (McNiff & Whitehead, 2011). Figure (2) below shows the cyclic model developed by Sousa (2011) and which fits with Mayoh & Onwegbuzie's (2013)

perspective to describe the stages of an action research study design. The application of the model to this study is outlined in Figures (3) and (4).

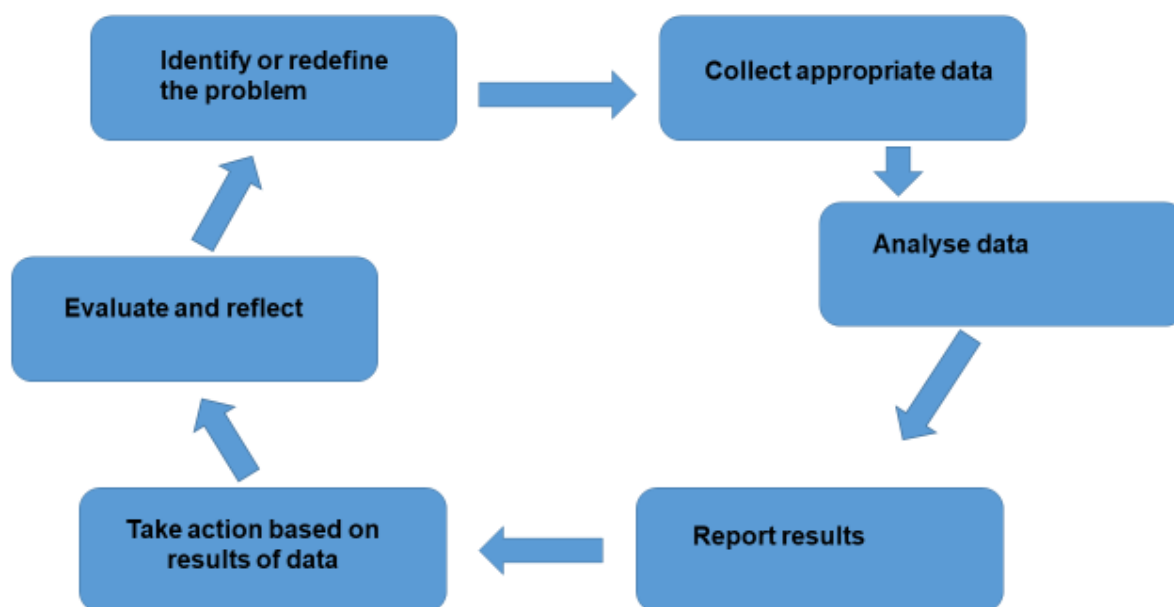


Figure 2: The six steps in the action research cycle (Sousa, 2011)

Since its inception in the 1940's, action research has been variously defined and explained (Waterman & Timman et al, 2001). As a research methodology it has been utilised in a variety of professional settings such as healthcare, education and psychology/psychotherapy. It's strength for use within this phenomenologically inspired study is that it is co-operative, supporting activity among practitioners searching for solutions to everyday, real problems experienced in these settings or looking for ways to improve practice (Waterman & Tillen et al 2001, Rowan, 2001, Heron & Reason, 2001, Day, Higgins & Loch, 2009, Cohen, Manion & Morrison, 2011, Mahani & Molki, 2012, Holloway & Wheeler, 2013, Mayoh & Onwegbuzie, 2013).

Action research thus becomes an approach that can be seen as fitting within and supporting research within a phenomenological paradigm. It facilitated the discipline specific approach chosen, to produce practical knowledge (Reason & Bradbury 2013), contributing to the wellbeing of participants and the communities from whence they came. In this study, it indirectly benefited the participants through the steps used to develop the conceptual framework and model. Ultimately this should contribute to the wellbeing of the lesbian and bisexual women with cancer, their partners and potentially impact on the wider LGBT community.

Although this study argues that it uses a cyclic approach (Sousa 2011), it was decided that the activities made up the two modified cycles presented in a linear format as shown in Figures (3) and (4) subsumed within the modified phenomenological approach. Apart from the documentary data, all data analysis followed the processes given for phenomenological data sets. The key elements of use of modified bracketing, together with reflection and reflexivity were also integral to the study. Thus, in keeping with the focus of this project and my own professional practice as a nurse and therapist, this study has remained firmly anchored within the philosophy of phenomenology.

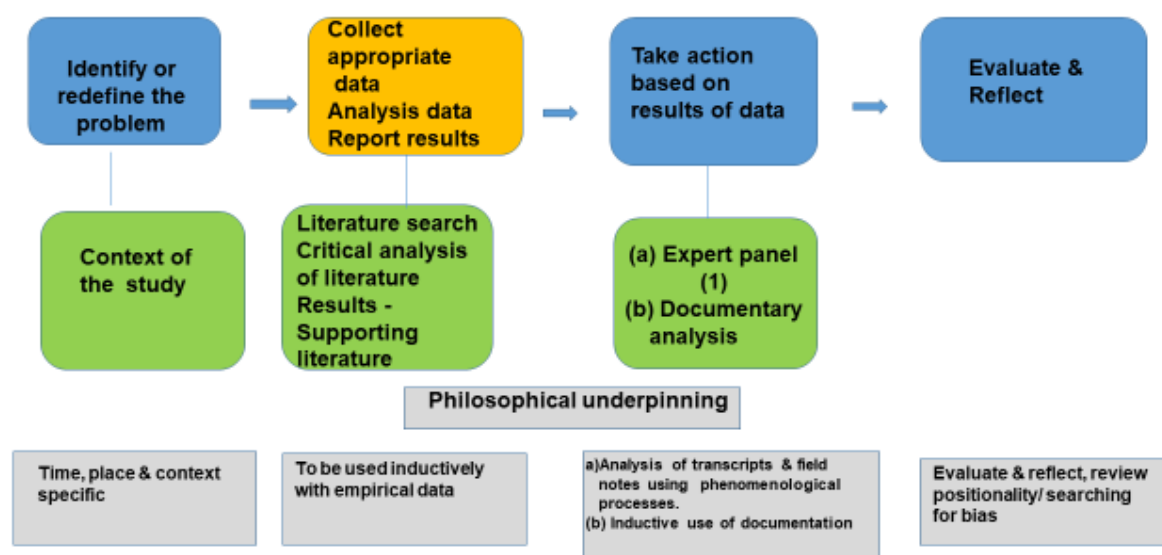


Figure (3) steps and activities within the modified action research cycle one

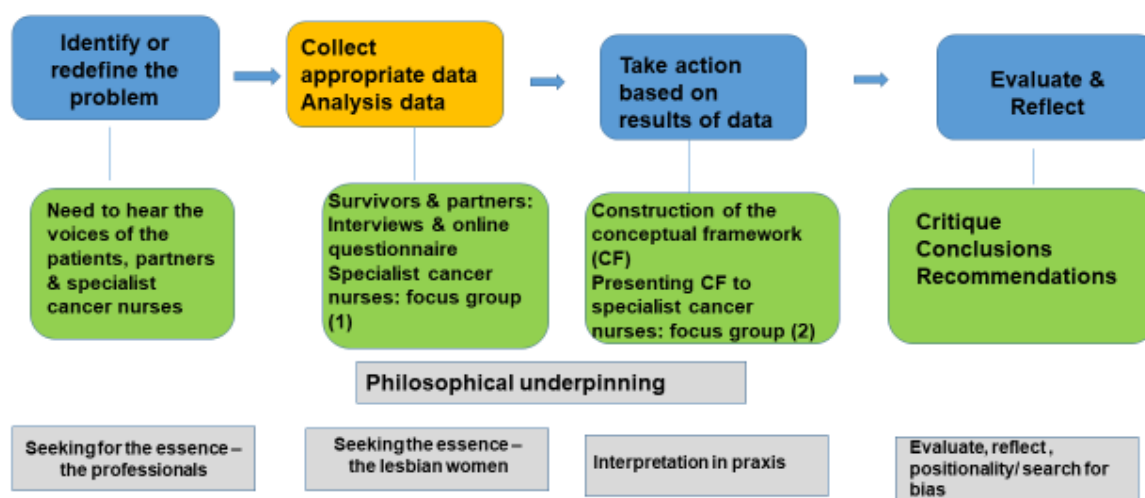


Figure (4) steps and activities within the modified action research cycle two

Methodological rigour and positionality

Traditionally in empirical research the measures of reliability and validity are used to assess the quality of a study. However, as Denzin & Lincoln (2011) and Torbin & Begley (2004) point out it is not easy to apply these measures to qualitative studies. They argue that the essence of qualitative research is probing and exploration and therefore measures of reliability, primarily designed to assess repeatability are inappropriate. Similarly phenomenology is designed to gain insights in areas where there is little knowledge it is not possible to use all aspects of validity as this set of measures were developed to assess whether the research has measured what it set out to measure. Instead they advocate use the measures originally developed by constructionists Guba, & Lincoln (1989) of trustworthiness and authenticity.

In the last three decades these have been developed further and distinctions have emerged depending on the methods chosen (Denzin & Lincoln, 2011, Englander, 2012). For descriptive phenomenology in regards to trustworthiness the following areas were carefully considered – credibility, dependability, transferability and confirmability. For, authenticity whilst accepting that most of the measures within this element are assessed at completion of the project, where possible the individual components were included and the extent to which they were applied will be discussed in the study critique, these are criteria of fairness, ontological, educative,

catalytic and tactical authenticity (Guba & Lincoln, 1989, Tobin & Begley, 2004, Lincoln, Lynham & Guba, 2011).

To facilitate assessment of the processes used and to provide evidence of consistency and rigour an audit trail was generated. This included documentation throughout the design, implementation and analysis stages. 'Memo - ing' from field notes (Miles & Huberman, 1984), were used to capture the non-verbal elements of the interviews and focus groups to make initial notes of key issues identified within the interviews. These memos were augmented by a reflective researcher diary which aided my processing and reflexivity as well as providing evidence of my 'decision making trail' regarding theoretical, methodological and analytic choices (Koch, 1994, 2006, Wall & Glenn et al, 2004).

Positionality as part of the methodological rigour

As the initial section on descriptive phenomenology and positionality indicated (pages 3, 4 and 16), I had to take account of my own biases and constructs, and when considering methodological rigour, this included the notion of reflexivity and through this, the identification of my 'conceptual baggage' as an integral element of phenomenological reduction or epoche'. (Giorgi, 2009, Finlay, 2011). Conceptual baggage is defined by Kirby & McKenna (1989) as the researcher's record of thoughts and ideas about the research question, at the beginning and throughout the research process. This is the process through which personal assumptions are stated and considered regarding the topic being researched, and the research processes being used. It is further argued, that the researcher's conceptual baggage can add another, often overlooked dimension to the data. By making their thoughts and experiences explicit the researcher may not only reduce bias but also add another layer of data for investigation (Wall & Glenn et al, 2004). Therefore in this study, the field notes and a reflective and reflexive diary were used continually to review the researcher's role in, and impact on, the study thus adding to the methodological rigour.

Ethical considerations

All research project presents ethical issues, with consideration and application of ethical principles being at the heart of any study (Miller, Birch et al, 2012). This is particularly the case when the study looks to examine the experiences of vulnerable and /or marginalised groups, and /or exploring sensitive issues (Ellsberg & Heise, 2002, Liamputtong, 2007, Martin & Meezan, 2008, Meezan & Martin, 2012) – such as the psychosexual and relationship issues experienced by the lesbian and bisexual women within this study. The ethical starting point for any research project should be whether there is the need to undertake the research (Jacobsen & Landau, 2003). The motivation for the researcher undertaking the study arose

from details emerging as a psychosexual and relationship therapist, voluntary input into a support group for breast cancer survivors (discussing and supporting the women with issues pertaining to their sexuality and intimate relationships) and discussions with staff and volunteers at a local lesbian, gay, bisexual and transgender health project. What became apparent was the lack of specific information and support available with little being offered to lesbian and bisexual women. It was found that the majority of available literature (including that provided to the women from support organisations) was heterosexually orientated. The focus of the study therefore grew out of an expressed need of women from both the support group and a local lesbian, gay, bisexual and transgender health group, together with the dearth of evidence based literature to guide practice in this area.

Given the sensitive nature of the research and the centrality of the ethical elements of the study, ethical approval was sought and given via the Faculty of Health Research Ethics Committee (please note that the Faculty of Health became the Faculty of Health, Education and Life Sciences during the period of this study, therefore further ethics approvals were sought and gained from the ethics committee for the reconfigured faculty) (see appendices one - four). Whilst the ethical principles of Beauchamp and Childress (2013) were originally formulated to guide ethical practice for clinical trials, and have been open to criticism with regards to their appropriateness for phenomenological studies (Greenfield & Jenson, 2010), these together with the works of Martin & Meezan (2008), Seedhouse (2009) and Miller & Birch et al (2012) provided useful frameworks to guide the researcher to check that the ethical issues within the study were identified and addressed. In all stages of the study, efforts were made to address the principles of autonomy, beneficence, justice, non-maleficence and fidelity (Beauchamp & Childress, 2013).

In research terms the principle of autonomy requires that the researcher discloses all the information necessary for autonomous decision making to the participants. Thus allowing the individuals to make an informed choice, free from coercion or undue pressure (Beauchamp & Childress, 2013, Miller & Birch, 2012). Within the study voluntary participation was emphasised throughout, beginning with the information provided in the recruiting material and participation information sheets (see appendices seven (b) and seven (c) for examples) and was again revisited at the time of the interviews and focus groups. The right to withdraw from the study at any point was also conveyed via these means. The purpose of the study, appropriate methods for recruitment, what was being asked of the participants and the support available for them were also discussed with the staff of the LGBT health project centre and the programme lead for the specialist cancer practitioners post registration programme and the conference organising committee to ensure they were aware of the non-coercive nature of the project and aware of what information to give any potential participants who might

approach them for clarification. Thus gate keeper consent was sort and given for accessing participants and for the use of premises for participant interviews, focus groups and expert panel was gained.

A key aspect of the principle of autonomy is the nature of informed consent (Beauchamp and Childress 2013). In the case of this study the lesbian and sexual women were being asked to consent to inclusion in the study through undertaking an interview or questionnaire. Whilst the expert cancer practitioners were asked to consent to participate in an expert panel workshops and a questionnaire. The cancer specialist nurses were asked to consent focus groups. All participants consented to data analysis and study dissemination, rather than the inclusion in a clinical procedure. Nevertheless, the guidance offered by Beauchamp & Childress (2013) in relation to informed consent was utilised, informed consent was seen to be an ongoing process rather than stopping at the point of the participants signing the consent form. Prior to any data collection participants were provided with a full explanation of the procedures involved, the rationale for undertaking these, together with checking the participants were aware that they could withdraw from the study at any point without giving the reasons and without penalty.

Beneficence refers to the moral obligation to act for the benefit of others. This obligation may include safeguarding the rights of others, preventing harm and removing conditions that will be harmful, together with helping people who are vulnerable and /or disenfranchised (Beauchamp & Childress, 2013, Greenfield & Jenson, 2010). It was anticipated that by giving voice to the specific experiences of frequently marginalised women, and these being made available to specialist health care practitioners, findings from the study would help to improve the quality of the care provided to these women and their partners. It was also seen as important that the participants were given autonomy and the right to control their own setting for the interviews, this was especially important for women who may have had mobility problems, and for those who may have felt afraid or inhibited attending the LGBT health project centre.

Related to the principle of beneficence is the principle of justice which is concerned with the fair selection of participants, together with a fair distribution of benefits and burdens of research. The concept of distributive justice is seen as paramount in both ensuring that no segment of the population is unfairly burdened with the harms of research, whilst also ensuring that no individual or group is neglected or discriminated against, or that vulnerable individuals do not feel pressured into participation or exploited (Beauchamp & Childress, 2013, Miller & Birch et al ,2012). In this context, justice connotes fairness and equity for all participants in research and is especially important with regards to the potential vulnerability of the

participants due to their sexual minority and health status. To this end all of the elements previously outlined and addressed in the autonomy and beneficence sections are equally applicable with regards to justice within the study. In addition, I ensured that the participants were aware of their anonymity and confidentiality as discussed in relation to non - maleficence.

Throughout, I made sure that the participants were treated equally, by allowing them the time to tell their stories, at their own pace and within a setting of their choice. I also made it evident to the participants that I valued what they were saying equally, this was seen as especially important given the very personal nature of the topics being discussed for the lesbian and bisexual women and partners, but also for the health care professionals who may not have had the opportunity to discuss these issues in practice previously. The nature of sexuality is intensely personal and challenges individuals at a fundamental level, thus talking to both the women and the healthcare professionals had the potential to stir deeply held beliefs and attitudes. It linked with non-maleficence (the researcher doing no harm).

The principle of non-maleficence requires that the researcher does no harm whilst undertaking the research (Beauchamp & Childress, 2013, Miller & Birch et al, 2012). The anonymity of the participants was ensured by the safe/secure storage of the audio recorded interviews and focus groups (being locked in a secure cupboard, recorded information being stored on a password protected computer and encrypted data stick) and the removal of identifying information from the transcriptions, these transcriptions being kept separate from the audio recordings, and being available only to myself and in an anonymised format to my supervisors. The online questionnaires for both the expert panel and the lesbian and bisexual women and partners were anonymous, with no identifying information. The electronic information was secured as per the interview and focus group data. In addition, it was essential that the participants were assured of the confidentiality of their participation and of the information they were sharing. It was important that they were made aware of exceptions to confidentiality i.e. situations where a participant or third party needs to be protected from damage, so this was made explicit to all participants from the outset of the study. Fortunately, the need to breach confidentiality was not necessary in this study.

Related to the principles justice and non - maleficence is the principle of fidelity, which is concerned with the building of trust between researcher and participants. Due to the sensitive nature of the study this was seen as crucial, therefore every effort was made to safeguard the participants from potential harm arising from participating in the study. The interviews, questionnaires, expert panel workshops and focus groups were undertaken as outlined in the participant information literature. Furthermore, I utilised my experience in building appropriate

therapeutic relationships to build the trust of participants, enhanced by outlining both verbally and in writing the measures being taken to ensure their confidentiality and anonymity.

Due to the sensitive nature of the study topic/s there was the potential for negative psychological effects, this being particularly so in the case of potentially personal, emotive and what could be seen as intrusive questioning (Mauthner, Birch & Jessop 2002). I therefore sought to be sensitive in my questioning, engaging the interviewing and questioning skills developed as a psychosexual and relationship therapist to good effect. This training and experience was very useful as it afforded me more credibility with the participants and also provided them with greater psychological safety. The sensitive subjects around sexuality were ones that, as a therapist I was very much at ease with, this afforded greater comfort with the discussion of these personal issues with all of the participants. In addition, in keeping with feminist interviewing principles (Speedy, 1991, Campbell & Adams et al, 2009) I was also prepared to work through any distress experienced by participants during the interview should this be necessary, together with providing participants with the contact details of appropriate counselling services should these be needed. I was also mindful, from both my experience as a therapist and researcher of the need to safeguard my own emotional wellbeing, as it was anticipated that I would find some of the women's stories personally distressing. I therefore arranged for the provision of counselling support through my professional contacts (my previous therapy supervisor - familiar with the issues being presented), together with regular meetings with my study supervisors. These were considered as essential safe arenas to debrief from the sometimes emotionally - challenging stories being told by the participants.

Each data set required a unique group of participants and therefore sampling issues were considered at the appropriate points in the study. But throughout the study ethical principles were adhered to as each group of participants were recruited. As will be seen in the later phases of the research journey it was necessary to return to the research ethics committee for additional approval for amendments to the recruitment strategy and methods needed in order to move the study forward. These amendments allowed for wider participant recruitment and data collection, whilst remaining true to the original aims of the study.

Chapter Three: Journey Phase One (B) - The Starting Point

Although in phenomenological studies the review of current literature normally takes place later on in the study, as a practitioner a review of the context of the background and the focus of the study was undertaken at the start.

Context:

The place of sexuality and sexual health (incorporating psychosexual health) in healthcare and cancer care practice

There are few definitions of sexuality, Woods (1987) in her seminal work in this area related to health care practice views sexuality as a central part of being human throughout life. She states that sexuality is made up of the inter - related concepts of sexual self-concept, sexual role relationships and sexual function. Sexuality is experienced and expressed in our thoughts, fantasies, desires, beliefs, values, attitudes and behaviours. Whilst sexual health is seen as a “state of physical, emotional, mental and social well-being in relation to sexuality, it is not merely the absence of disease, dysfunction or infirmity” (World Health Organization, 2002 page 5). Additionally WHO (1975) identified the core components of sexual health as being: “a capacity to enjoy and control sexual and reproductive behaviour in accordance with a social and personal ethic, freedom from fear, shame, guilt, false belief and other psychological factors and freedom from organic disorders, diseases and deficiencies that interfere with sexual and reproductive functions” (WHO, 1975, page 6 para 5). In many ways these core elements of sexual health, influenced by the power of the medical profession adopt a rather biomedical approach, which directly impacts on how policy makers and healthcare practitioners view and manage societies and individuals sexual health and wellbeing (Bunton & Peterson, 1997)

It was three decades ago that Woods (1987) suggested that an individual's sexual self-concept is how they view themselves as a man or woman and encompasses that person's self-esteem and body image. Perhaps because of the era in which this was written this does not take account of transgendered people, whose sexual self-concept should clearly be considered by nurses and other healthcare practitioners. Sexual role relationships were described as all the relationships in which an individual is involved within their world, not just their sexual ones (Woods, 1987). These relationships therefore include those with partners, children, parents,

friends and colleagues. Sexual function is more self - explanatory and is the component of sexuality on which many patients focus, especially if their sexual abilities are altered as a result of ill health or disability. Psychosexual health relates to the issues of sexual anxiety and distress which an individual may develop as a result of the sexual self-concept being threatened by illness, altered sexual functioning or relationship difficulties (Irwin, 2002). It is seen to be an integral part of an individual's overall sexual health. Many individuals, including nurses and other healthcare professionals, possess a narrow view of what sexual intimacy means and the norms surrounding it, as well as a poor understanding of the mechanisms of sexual functioning (De Vocht et al, 2011). It is therefore important that nurses and HCPs are able to provide accurate information and education to patients about the mechanics of sexual function, while remembering the importance of viewing sexuality holistically.

In response to the identified need for research in this field the decision was made to start with a review of the current readiness of nurses and other health care practitioners to incorporate sexuality, sexual and psychosexual health generally into their patient care, before moving on to working with lesbian and bisexual women. During this process it soon became clear that much of the research evidence appeared rather dated, with little research post De Vocht (2011), a decision was therefore made to expand the review to include an historical examination of the past 40 years. Seeking literature pertaining to these areas, with a focus on nursing practice.

This search revealed that from 1976 onwards studies pertaining to nursing suggested that there was a consumer demand for assistance with sexuality, (Woods & Mandetta, 1976, Krueger & Hassell, et al, 1979, Burgener, 1985, McCormick & McDougal - Thompson, 1986, Young, 1987, Baggs & Karch, 1987). While Waterhouse & Metcalfe (1991) indicated that patients prefer nurses to initiate such discussions. The studies found that there was a clear role expectation of nurses in regards to patient's sexuality, but not what constituted the expected role. Weinburg (1982) and Woods (1987) suggested that the nurse's role is one of educator and counsellor, however Poorman (1988) warned that it would be inappropriate for nurses to attempt to function as 'mini sex therapists', and therefore they should be aware of the limitations of their knowledge and skills. Although Woods & Mandetta (1976) a decade earlier had demonstrated the acceptance of this educator/counsellor role by some qualified staff. However, it is important to bear in mind the Trans - Atlantic nature of these studies and suggestions. Indeed, Hicks (1980) questioned the universal acceptance of sexuality as a legitimate area of nursing concern. Whilst Savage (1989) urged nurses and nurse educators to be realistic in their role expectations in this area. These conflicting views and

recommendations further confuse the issue as to what exactly nurses should know or do in regards to patient's sexuality.

Never the less numerous authors have demonstrated that nurses have poor sexual knowledge (Mandetta & Woods, 1974, Lief & Payne, 1975, Kuczynski, 1980, Greener & Reagan, 1986, Girts, 1990), and furthermore, they suggested that nurses perpetuate sexual myths. Indeed Lief & Payne (1975) found that 76 percent of the nurses in their study believed that there were two types of physiological orgasmic response, and that masturbation caused mental and emotional instability. Belief of these myths persisted throughout this period with studies throughout the 1980's and 1990's continuing to demonstrate this lack of sexual knowledge, both in the USA and UK (Greener & Reagan, 1986, Webb, 1988, Thomas, 1990).

Other studies suggested that nurses need to possess certain characteristics if they were to operate successfully as 'sexuality educators /counsellors' (Krozy, 1978, Kuczynski, 1980, Webb & Askham, 1987, Webb, 1988, Thomas, 1990). These were: up to date sexual knowledge, comfort with their own and the patients sexuality, resolution of own sexual identity and overall adjustment, the ability to speak openly, honestly and confidentiality about sexuality issues, together with the skills of interviewing and of using oneself therapeutically. However, for the most part these authors make no suggestions of ways of developing such characteristics and skills with staff.

There were, however, several studies that included an exploration of the educators readiness to develop students as sexually comfortable nurses (Woods & Madetta, 1976, Zalar, 1982, Webb, 1985), with Webb & Askham (1987) expressing their concern about the readiness of teacher preparation in this area. Randell (1989) found that 33 percent of teachers believed lesbians to be child molesters and at high risk of spreading HIV infection; thus demonstrating a dangerously poor understanding of sexual issues. The attitudes held by the educators were seen to reflect those of the practitioners (Thomas, 1990). Woods & Mandetta (1976) found that most colleges of nursing gave only cursory support for sexuality to be included in the curriculum. Zalar (1982) concurred demonstrating that most teachers did not see sexuality as an essential element in a nursing curriculum.

Where 'sexuality education' was occurring the aims of this appeared to be consistent. Those being: increasing sexual knowledge, bringing about attitudinal change through increasing students self - awareness of their values, attitudes and prejudices, and helping them cope with sexual problems arising from clinical practice (Mims & Yeaworth, 1974, Woods & Mandetta, 1976, Frazer & Smith 1982, Thomas, 1990). Although the educational aims were uniform, the content and teaching strategies used were diverse. Most authors recommended using small

group work / discussions, following lead lectures, trigger films, videos or journal articles (Mims & Yeaworth, 1974, Woods & Mandetta, 1976, Frazer, 1982, Thomas, 1990). Experiential teaching /learning strategies featured highly, especially with regards to values clarification and communication skills (where role play was recommended). Gaming and 'fish bowling' - a teaching strategy in which students ask questions, present opinions, and share information when they sit in the "fishbowl" circle, while the other students sit on the outside of the circle listen carefully to the ideas presented and pay attention to process, the roles are then reversed (McManus & Vincent et al, 1993) were used effectively by Woods & Mandetta (1976) and Frazer & Smith (1982). It is suggested that although these courses /programmes were effective vehicles for enlarging knowledge, it is necessary to move beyond the cognitive domain towards the affective realms in order to approach and shape attitudes and behaviours. Moving forward to a more recent timeframe studies showed that nurses and other HCP's still have poor sexual knowledge (Girts, 1990, Olsson, Berglund & Larsson, et al, 2012). Furthermore, the studies continue to suggest that HCP's need to have certain characteristics if they are to address sexuality and sexual issues in practice, including having up to date sexual /sexuality knowledge (especially related to the specific ill health problems of the patients in their care) (Saunamaki, Andersson & Engstrom ,2010, Zeng, Lui & Loke, 2011). Of central importance is comfort in their own and about their patient's sexuality, resolution of their own sexual identity and overall adjustment to this self-knowledge. Together with an ability to speak openly, honestly and confidentially about sexuality issues along with the skills of interviewing and counselling (Girts, 1990, Hordern,, Street, 2007, Olsson, Berglund & Maria Larsson, et al, 2012).

The literature has continued to support the earlier suggestion that there is consumer demand for assistance with sexuality (RCN, 2000, Haboubi & Lincoln, 2003, Morris & Magnan et al 2005, Saunamaki, Andersson & Engstrom, 2010, Zeng, Liu & Loke, 2011). These authors have also indicated that patients prefer the HCP's to initiate such discussions, thereby giving them 'permission' to discuss their concerns, very much reflecting the historical situation identified above. Although many nurses and other HCP's would agree that the sexuality assessment of patients is part of holistic care (Haboubi & Lincoln, 2003), for a number of reasons, they do not address patients' sexuality concerns within their own healthcare practice (Higgins et al, 2006).

Despite changes in societal attitudes in the UK towards sexuality over the past 40 years, the more recent papers indicate that a number of the barriers identified in the historical perspective persist. These prevent HCP's from addressing their patients' sexuality, sexual health and psychosexual health issues. The main barrier being the HCP's discomfort and embarrassment

in addressing these issues, together with their perception that a patient's sexuality is too personal for them to discuss. In addition, practitioners cite lack of available privacy for such personal discussions and furthermore that patients are too ill to be concerned with sexuality (Saunamaki, Andersson & Engstrom, 2010, Zeng, Liu & Loke, 2011).

Overall the studies have shown that nurses and other HCP's do have the poor sexual knowledge cited by De Vocht (2011). The studies also continue to suggest that HCP's do need to have specific characteristics if they are to be able to address sexuality issues in practice. These include having up to date sexual /sexuality knowledge (especially related to the specific ill health problems of the patients in their care (Saunamaki, Andersson & Engstrom, 2010, Zeng, Liu & Loke, 2011). Having explored the evidence in regards to the place of sexuality and sexual health in healthcare generally, together with the practitioner's readiness to incorporate these as part of the care provided to their patients, attention then turned to the specific field of cancer care.

The importance of incorporating sexuality and sexual health assessment and interventions into cancer care

Cancer and the subsequent treatment regimens are well known to negatively impact on women's sexuality and relationships (Rice, 2000, Hughes, 2008, Sadosky et al, 2010, Melisko, Goldman & Rugo, 2010, Olsson, Berglund & Maria Larsson, et al, 2012). The physiological impact is known to include reductions in sexual desire, arousal, orgasm, sensations - general, breast and clitoral and sexual pleasure. Together with increased vaginal dryness and dyspareunia (Sadosky et al, 2010, Melisko, Goldman & Rugo, 2010). In addition, it is recognised that both cancer and treatments can negatively affect a woman's body image, this can be in the short term (during treatment) resulting from interventions such as chemotherapy leading to hair loss, or longer term either as a result of continued treatment such as aromatase inhibitors leading to weight gain or resulting from surgery for example mastectomy (Fobair & Stewart et al, 2006, Sadosky et al, 2010). Furthermore, whilst it is important to recognise the physiological changes in sexual function brought about through cancer and treatments, it is important to remember that the psychological and social consequences also impact directly on the women and their partners' sexual and intimate feelings and behaviours (Schover, 1991)

The importance of assessing and addressing the sexuality and sexual health issues of patients with a diagnosis and undergoing treatment for cancer are well known (Fobair, Stewart, &

Chang, et al, 2006, Hughes, 2008, Krebs, 2008, Tierney, 2008, Sadovsky, Basson & Krychman et al, 2010). Individuals with cancer express the need to talk to and be provided with support from HCP's in regards to their sexuality. However the practitioners, despite recognising and agreeing the importance of talking to patients failed to do so due to their own attitudes, lack of knowledge and skills (Lavin & Hyde, 2006, Beck & Justham, 2009, Olsson, Berglund & Maria Larsson et al, 2012). Indeed Lavin & Hyde (2006) demonstrated that although the cancer nurses wished to incorporate 'sexuality care' into their practice they felt ill equipped to do so by virtue of little or no input within either their pre or post registration education to do so.

All of the above provides insight into the position of sexuality and sexual health in healthcare and healthcare practice generally together with the situation in regards to cancer and adjunctive treatments. The primary focus of this research project revolves around the experiences of lesbian and bisexual women who have been diagnosed with and treated for cancer. Therefore it was necessary firstly to explore briefly the history of homosexuality and lesbian relationships in the U.K. Secondly to explore and gain insight into the HCP's attitudes towards caring for LGBT patients, together with an examination of the knowledge and skills required to provide appropriate care to LGBT patients. Lastly, it was important to critically examine the actual and potential impact an individual's sexual orientation may have on their health and access to healthcare – specifically focussing on lesbian and bisexual women.

Societal perceptions and attitudes towards homosexuality in the UK

To be able to understand the specific differences presented when working with lesbian and bisexual women it is important to have an understanding of the history surrounding homosexuality, which led to the hidden nature of gay and lesbian relationships. It is argued (Twomey, 2008, Rondahl, 2008, 2009) that if a person is excluded from mainstream society, experience sexual oppression and /or their voice is silenced, this will have a negative effect on their health and wellbeing (including their psychological health). Further, they may internalise these negative messages and come to believe what the dominant group says about them i.e. internalised homophobia. For some lesbians this experience contributes to the higher levels of mental health problems experienced within the lesbian community (King & McKeown, 2003) and also makes some lesbian and bisexual women fearful of disclosing their sexual orientation to HCP's for fear of being discriminated against. In addition, some older lesbians will have had very negative experiences due to their orientation e.g. having undergone aversion therapy and incarcerated within mental health facilities to 'cure' their homosexuality

(Stonewall, 2015). Despite the removal of homosexuality from the official APA list of mental illness in 1973 (American Psychiatric Association, 1973) and WHO in 1992 (WHO, 1992) together with being strongly condemned by the major UK psychiatric and psychological organisations (UK Council for Psychotherapy, 2014) aversion therapy for homosexuality is still not banned in the UK and other parts of the Western World.

The fear of discrimination which is felt by many lesbians, bisexual women and gay men in the UK is really grounded in the historical background of the persecution for homosexuality in this country. When looking back on this history ranging from the open persecution of 'sodomites' and death by burning in medieval times, hence the use of the derisory term 'fagott' for gay men. Through to punitive legalisation and pathologising (and commensurate treatments) throughout the 18th – 21st centuries, with homosexuals being seen as either bad or mad (Oram & Turnbull, 2001, Stonewall, 2015). It is hardly surprising that lesbians, bisexual and gay men have often felt compelled to keep their relationships hidden for fear of severe punishment.

The situation is now better with attitudes being more liberal and open minded in most places in the world, especially in terms of the legality of gay and lesbian relationships/sex. There are still places in the world where homosexuality remains illegal and in some countries, such as Nigeria and Saudi Arabia is punishable by death (Stonewall, 2016). When working with a multi-cultural patient group it is important for HCPs to have some understanding of the position in the patient's country of origin. Furthermore, whilst homosexuality may be legal there, as in the UK there is always the risk of a prevailing homophobic attitude by either the majority population or sub sets of this, leading to persecution and hate crimes (Guasp, Gammon & Ellison, 2013).

Lesbian sexual relationships across time have changed and developed over time, often reflecting the prevailing societal norms and attitudes. From the times of female friendships or 'Bostonian Marriages' (seen as non-sexual), to greater sexual experimentation and rejection of the heterosexual 'male model' which resulted from the feminist lesbian movement in the 1970's (Oram & Turnbull, 2001, Jennings 2007 a) Jennings, 2007 b). Experimenting in different relationship configurations and not feeling the need to conform to heterosexual norms, lesbians creating their own ways of developing and maintaining relationships, lovers becoming friends and then lovers once more (Oram & Turnbull, 2001) has been common place within the lesbian community. Another common experience was serial monogamy (Garnets & Kimmel, 2003). Reflecting the complex social and political views many myths exist regarding lesbian sex, including lesbian sex occurs constantly (as lesbians, like their gay male friends are obsessed with sex) or it occurs infrequently – so called lesbian bed death (Blumstein & Schwartz, 1983, Nichols, 1987, 2004) and lesbian sex is just kissing and cuddling – not real /genital sex (Jennings, 2007). Whilst in reality, lesbian sex and sexual

relationships are diverse ranging from those with no or limited genital sex through to Bondage and Discipline, Dominance and Submission, Sadism and Masochism (BDSM) (Iasenza, 2002, Nichols, 2004, Roson & Milhausen et al, 2012, Cohen & Byers, 2014). The concept of lesbian bed death has been refuted by many researchers (Bressler & Lavender, 1986, Coleman & Hoon et al, 1983, Iasenza, 2002, Nichols, 2004) and whilst previously it was a common place belief within some elements of the lesbian community it has become a source of amusement (Nichols, 2004). Nichols (2004) also suggests that lesbian bed death appears to be a historically dated phenomenon. Younger lesbians are freer of sexual inhibitions and less restrained by shame about their sexuality, with greater sexual and gender fluidity. Several authors have suggested that there has been a move over the past decade to more polyamory within lesbian relationships, that is concurrent, multiple lengthy relationships involving some degree of commitment (Roson & Milhausen et al, 2012, Cohen & Byers, 2014).

In the past the hidden nature of lesbian relationships and fear of homophobia meant that many lesbians had to rely heavily on the lesbian and gay community for their support and 'family' (Weston, 1991). This would often mean that former partners became friends and there was a continued supportive, but not sexual relationship in place (Oram & Turnbull, 2001, Jennings, 2007 (a) Jennings, 2007 (b)). This difference from the dynamics found amongst heterosexuals is important for healthcare professionals to understand, as they may care for women where the 'community' is family. Also as a result of the homophobia and the prejudice experienced, the lesbian community has in the past and to some extent continues to be a 'closed' to outsiders, only sharing the positive images of lesbian relationships (Ristock, 2002, Jennings, 2007b). The result of this has been the hidden nature of problems such as domestic abuse, mental health problems, drug and alcohol abuse problems, all of which impact directly and negatively on lesbian relationships (Lockhart & White et al, 1994, Ristock, 2002, Eaton & Kaufman et al, 2008).

A prevailing myth about lesbians and their relationships is that lesbians have either never had or do not have sex with men (Nichols, 1987, 2004). However, as long ago as the 1990's Kitzinger & Wilkinson (1995) showed that possibly 46% of lesbians have sex with men even after they had 'come out' as gay. Furthermore, Diamond (2003) demonstrated that with greater sexual and gender fluidity there was a lot of back and forth between lesbian, bisexual and heterosexual identities. A further myth is in part linked to this that is that lesbians don't have and /or do not want children (Jennings, 2007a). This is clearly not the case, as many lesbians bring to their relationships, children from previous heterosexual relationships or wish to pursue having children within their lesbian relationships through artificial insemination (Chabot & Ames, 2004)

Healthcare professional's attitudes to LGBT patients

Plazter & James (2000) identified that nurses/HCP's need to be prepared to offer culturally appropriate care for LGBT patients, and in many cases were not able to do so. Furthermore, Rondahl (2008, 2011) and Steppe (2013) identified that attitudes of heterosexism and homophobia create barriers to providing appropriate care. While evidence suggests homophobia in health care is declining, Plazter & James (2000), Rondahl (2008) argues that heterosexism remains prevalent and negatively impacts LGBT patients. With heteronormativity being identified as the assumption that heterosexuality is a general norm within society. As a consequence of this heteronormativity LGBT patients are addressed and treated like heterosexuals with no account being taken of their unique and individual needs. Individuals are assumed to be heterosexual until they do or say something that disproves this assumption. Due to the negative history of homosexuality in the U.K. lesbians and gay men may choose to hide their sexual orientation and thus remain 'hidden' from HCP's, due to fear of negative attitudes and consequences. This may be especially true of older lesbians and gay men whose 'formative years' were lived in a homosexual hostile legislated world – where 'the love that dare not speak its name' (Douglas, 1894) was the lived reality of day to day life (Oram & Turnbull, 2001, Jennings, 2007).

Although early studies found that homophobia was common amongst nurses and HCP's and nursing and healthcare students (Eliason & Randall, 1991, Stiernborg, 1992, Eliason, 1998) more recent studies have shown a decline among these populations, possibly reflecting the changing societal and legal attitudes and environment (Boch, 2011, Dinkel, Patzel, McGuire, Rolfs & Purcell, 2007, Johnson, Smyer & Yucha 2010, Eliason, Dibble & DeJoseph, 2010, Steepe, 2013). However, Walls (2008) and Morrison & Dinkel (2012) have suggested that heterosexism is a more common form of bias than homophobia and whilst it is not as adversarial as homophobia it has been shown to impact negatively on the healthcare experiences of LGBT patients (Saulnier, 2002, Sinding, Barnoff, & Grassau, 2004, Rondahl, Innala, & Carlsson, 2006, Rondahl, Innala, & Carlsson, 2007, DeHart, 2008; Rondahl, Bruhner, & Lindhe, 2009, Rondahl, 2011).

Introduction to Cancers in Women

Globally the cancer burden is known to be increasing in both the developed and emerging countries. According to GLOBOCAN 2012, an estimated 14.1 million new cancer cases and 8.2 million cancer-related deaths occurred in 2012, compared with 12.7 million and 7.6 million, respectively, in 2008 (International Agency for Research on Cancer (IARC), 2012). As shown in Figure (5) globally, various cancers represent common challenges to women's health, with breast and colorectal cancer having the highest incidence rates.

Type of cancer	Incidence
Breast	1.7 million
Colorectal	614,304
Cervical	528,000
Ovarian	225,000

Figure 5: Global Incidence of Cancer in Women.

(International Agency for Research on Cancer, 2012)

Breast cancer is also the most common cause of cancer death among women (522, 000 deaths in 2012) and the most frequently diagnosed cancer among women in 140 of 184 countries worldwide, representing one in four of all cancers in women (IARC, 2012). The relationship to other cancers globally is given in Figure (6) below.

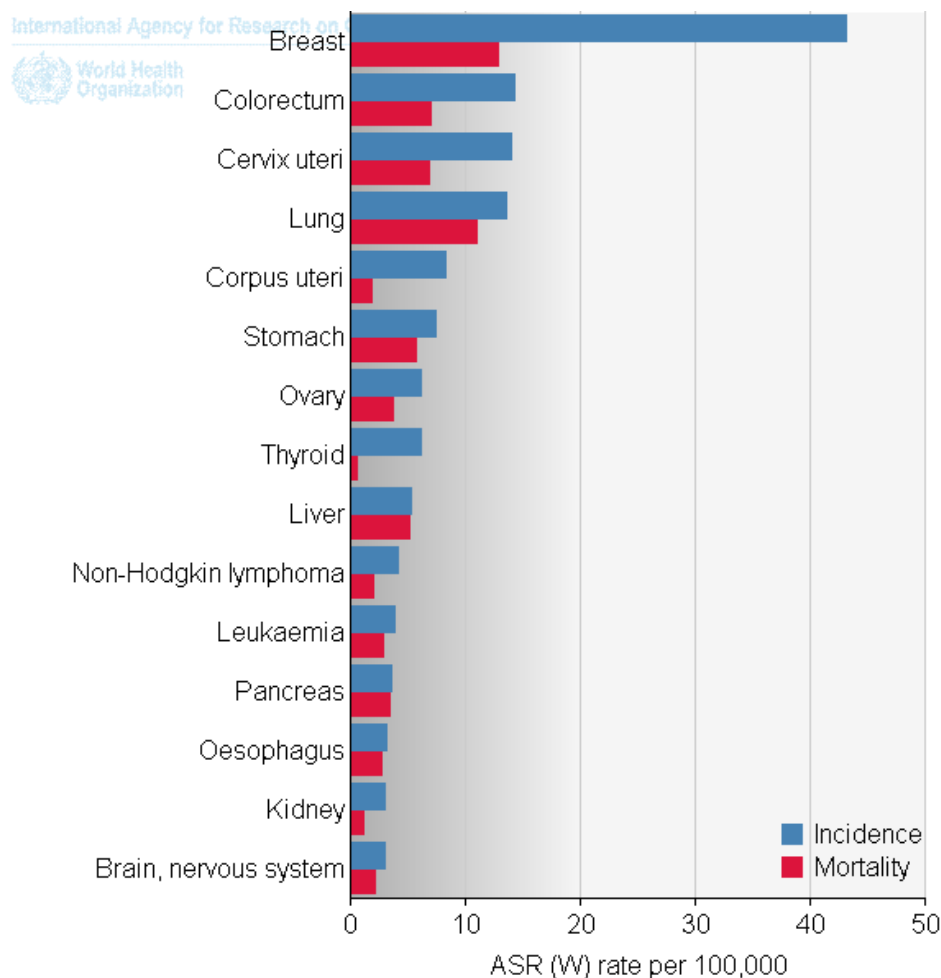


Figure 6: The 10 Most Commonly Diagnosed Cancers: 2012 Estimates Total Number and Percentage of New Cases Diagnose per Year, Worldwide (GLOBOCAN 2012, Cancer Incidence and Mortality Worldwide).

Reflecting the global picture in the UK breast cancer being the most common female cancer and second most common cancer cause of death after lung cancer. Overall, the incidence of new cases per year in 2013 (Cancer UK, 2015) was breast cancer - 53,696, Lung cancer – 46,403, Colorectal cancer - 18,200, Cervical cancer - 3,207 and Ovarian Cancer - 7,116.

Generally there is a fear around cancer, with a diagnosis often being seen as synonymous with a death sentence (Robb, Simon & Miles et al, 2014). However, many cancers now have a much better prognosis than previously, with earlier detection and more advanced treatment options (Cancer Research UK, 2015). As Figure (7) below shows women with breast and uterine (including cervical) cancer now have a very good chance of surviving cancer after 10 years. However, there is a less positive outlook for individuals with colorectal cancers. Furthermore, despite improvements in outcomes for some cancers for others e.g. ovarian and lung cancer the 10 year survival rates stubbornly remain relatively poor.

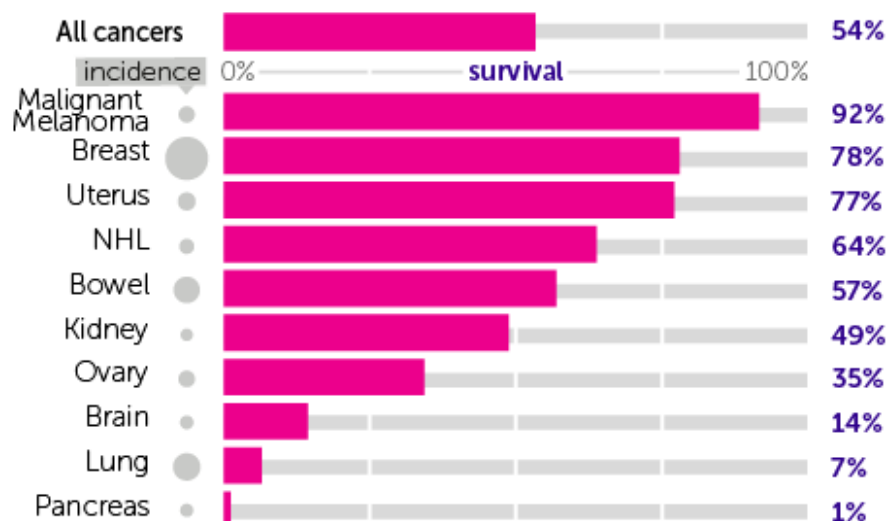


Figure 7

Cancer Research UK: Age-Standardised Ten-Year Net Survival, Selected Cancers, Adults (Aged 15-99), England and Wales, 2010-2011.

Overall women are living longer with cancer and the issues surrounding quality of life have become more important (Robb, Simon & Miles et al, 2014). This includes how the cancer and its treatments impacts upon the women's sexuality, sexual health and intimate relationships.

Impact of cancer and /or treatment on women's sexuality, sexual health and intimate relationships

Female and reproductive cancers and their treatments can negatively impact upon a women's sexuality and intimate relationships (Ganz & Rowland et al, 1999, Markopoulos & Tsaroucha et al, 2009, Emillee & Uusher et al, 2010). The treatment interventions used for cancer, including surgery, radiotherapy, chemotherapy and hormone treatment, all have a direct and indirect impact physiologically on the women's sexual function and sexuality. It is also important to recognise that the psychological and social consequences impact directly on the women and their partner's sexual and intimate feelings and behaviours. The role each of these plays in the individual cancers will now be briefly discussed and then returned to later in the chapter.

Gynaecological cancers

Surgery remains the primary treatment for most gynaecological cancers. Whilst pelvic radiotherapy is often either the primary or main adjunctive treatment for cervical and some endometrial cancers (Sadovsky & Basson, et al, 2010). In addition, the loss of ovarian

hormones from surgery and /or chemotherapy contributes to sexual difficulties, dysfunction and distress inducing menopausal symptoms and problems, such as vaginal dryness, hot flushes and fatigue (Park & Bae et al, 2007). Whilst it is difficult to gauge accurately the prevalence of these difficulties after specific cancers due to variations in sample size, different oncological stages and follow up times, studies have shown that between 30 – 63% of women who have undergone treatment for cervical cancer experience some sexual difficulties (Jenson & Groenwald et al, 2004, Frumovitz & Schover et al, 2005, Park & Bae et al, 2007, Greenwald & McCorkle 2008), with the majority of the women experiencing vaginal agglutination and stenosis within 3 months of radiotherapy leading to dyspareunia. Additionally, surgery for more advanced gynaecological cancers can include very extensive interventions including pelvic exenterations resulting in colostomies or ileoconduits which negatively impact the woman's body and self – image (Greimel & Winter et al, 2009). Oophorectomy (removal of the ovaries used for ovarian cancer) in addition to inducing the menopause signifies the loss of reproductive capacity, this in common with the treatments for other female cancers often leads to a challenge in the women's sense of femininity (Sadovsky & Basson et al, 2010).

Breast cancer

As with the gynaecological cancers the mainstay of treatment for breast cancer remains surgery with or without radiotherapy and chemotherapy. In addition, the use of long term selective oestrogen receptors e.g. Tamoxifen and aromatase inhibitors e.g. Letrozole have become routine treatment modalities. Treatment with these drugs and chemotherapy can lead to weight gain – on average 2.5 kg when receiving chemotherapy and 1.3 kg when taking Tamoxifen (Sadovsky, 2010). Breast surgery can cause scarring which can be both painful and disfiguring, whilst lymph node dissection can cause painful and distressing lymphedema. Radiotherapy and chemotherapy can cause skin fibrosis, respiratory and cardiac damage, fatigue, alopecia, nausea, vomiting and diarrhoea, all of which can result in an altered self - image and a reduced sense of femininity, negatively affecting sexual desire, response and satisfaction (Emillee, Ussher & Perz, 2010). Today it is generally accepted that women who have had treatment for breast cancer can experience sexual difficulties, including reduced desire, arousal, orgasmic pleasure and numbness of previously sensitive breasts. Together with increased vaginal dryness and dyspareunia (Ganz & Desmond et al, 1998, Fobair & Stewart et al, 2006, Emillee, Ussher & Perz, 2010, Melisko, Goldman & Rugo, 2010).

From the above, it can be seen that the diagnosis and treatment regimens of and for all types of female and reproductive cancers can lead to negative changes in the physical expression

of a woman's sexuality. These alterations however do not happen in isolation, they are set within a relational context – whether the woman is in an intimate relationship or not. The physical aspects of sexuality cannot be divorced from the psychological, social and relational context of the women's lives. Indeed several studies have shown that the quality of the women's relationships was a stronger predictor of sexual satisfaction, functioning and desire than any treatment induced damage (Speer & Hillenberg et al, 2005, Adler & Zenetti et al, 2008). Although the physical pain of cancer and treatment diminishes over time, the emotional pain experienced may persist as the woman mourns the loss of her former self, feeling that part of them has died, a feeling of a loss of the locus of control. These feelings may also be experienced by their partners, who are often at a loss as how best to help. The couple sometimes struggle to renegotiate their relationship in its entirety, including its sexual side (Emillee, Ussher & Perz, 2010). It has been suggested that healthcare professionals are ideally placed to help and support women and their partners to adapt to any post cancer changes. However, as Hawkins & Ussher et al, (2009) found only 30% of couples who were coping with breast cancer had discussed sexuality with a health care professional and they argue that this remains an area of quality of life neglected by HCPs. The potential reasons for this neglect will be discussed in the following sections.

The Cancer Context For Lesbian And Bisexual Women.

There is increasing evidence to suggest that lesbian and bisexual women may for a variety of factors be at more risk of developing some of the female and reproductive cancers. Reasons such as lifestyle i.e. obesity (Case et al, 2004, Boehmer et al, 2007), higher levels of alcohol consumption (King et al, 2003, Case et al, 2004, Fish, 2010, Brandenburg et al, 2007) and a reduced likelihood of having children and breastfeeding (Case et al, 2004, Zaritsky & Dibble 2010). Furthermore, some lesbian and bisexual women fail to recognise the need to participate in screening programmes (cervical and breast) through ignorance of actual risk and /or fear of being judged negatively by health care professionals (Case et al, 2004, Roberts & Patsdaughter et al, 2004, Polek, Hardle & Crowley,2008), Fish & Anthony, 2005, Henderson et al, 2009, Tracey et al, 2010).

In addition to creating a potential barrier to lesbian and bisexual women accessing appropriate screening services, some lesbian and bisexual women fear being negatively judged by and given sub optimal care by health care professionals should their sexual orientation be known (Boehmer & Case, 2004, Polek, Hardle & Crowley, 2008, Hunt & Dick, 2008, DH, 2010). This is especially important when considering the essential part played by the women's partner in providing psychological support, caring and support during a cancer diagnosis, treatment and

recovery (Fobair & Koopman et al, 2002, Boehmer, Linde & Freund, 2005, Jabson, Donatelle & Bowen 2011, White & Boehmer, 2012).

For many people, including lesbian and bisexual women, sexuality and its expression are seen as commensurate with feeling human and alive. It has been further suggested that this is especially important for patients with cancer and their partners (Emillee, Ussher & Perz, 2010). As previously outlined, cancer and many of its treatments can severely compromise a person's sexuality and their ability to express themselves sexually. As a result closeness, intimacy and sharing (along with other elements of sexual expression) can be avoided or neglected at a time when these could be so crucial and beneficial for the individual's wellbeing (de Votche, 2011). At a time when many people crave the closeness and comfort their intimate partner can provide, a barrier is erected which often both the person with cancer and their partner do not know how to breach.

Health care professionals have an important part to play in preventing this barrier being erected. In doing so with lesbian and bisexual women and their partners, they are also helping to overcome the actual or perceived barrier to appropriate health care that these women often believe exists for them as a 'hidden' sexuality /relationship (Fish, 2010). The relationships of lesbian and bisexual women are no less real than those of their heterosexual counterparts.

Having looked at what is known about the global incidence and prevalence female and reproductive cancers it was clear that these represent common challenges to women's health. However, it is unclear how many of the women effected would identify as being lesbian or bisexual, as information about sexual orientation is not routinely collected (Boehmer & Clark et al, 2011, NHS North West, 2011). However, it is known from census data that 1.6 percent of the UK population identify as lesbian or bisexual (Office for National Statistics, 2017). There is an evolving body of research, evidence and clinical literature that sheds light on the sexuality, psychosexual health and relationship sequelae of these cancers (especially breast cancer) and treatments, together with interventions which may aid adaptation and recovery of heterosexual women and their partners (Hughes, 2008, Sadovsky et al, 2010, Melisko, Goldman & Rugo, 2010). However, there was limited literature available in relation to lesbian and bisexual women, therefore a detailed literature search was undertaken to ascertain what studies could be found focussing on or exploring these areas as experienced by lesbians, bisexual women and women partnered women and their partners.

Lesbian and Bisexual Women Specific Literature Review

This review (undertaken in 2014) was seen as a key starting point of the study reviewing the available literature pertaining to the above areas. In keeping with the phenomenological

principles requiring reflexivity it was essential to ensure that there was no researcher bias when undertaking the review. Therefore, a critical review adopting a Participant Intervention Outcome (PIO) approach was undertaken and the literature search took place searching the Cochrane and Campbell Collaboration, together with Summon, Medline, Cinahl, ASSIA, PsychINFO /articles, criminology and NeLM (National electronic Library of Medicine) /NICE databases using specific search terms (sexuality, sexual dysfunction – physiological and psychological, lesbians, homosexual women, bisexuality and bisexual women, sexual minority women, cancers – breast, cervical, uterine, ovarian, vaginal and vulval). Despite utilising numerous search strings to ensure a wide location of studies only fifteen articles matching the PIO criteria were located. Of these only four met the selection criteria for critical review based on title and abstract, whilst two identified lesbians as a comparative group to heterosexual women. All the studies were with women who had been diagnosed and treated for breast cancer.

There was a plethora of information and literature in relation to chemotherapy, radiotherapy and surgical interventions used to treat cancer. In contrast to the paucity of information regarding sexuality. However, these were couched in general terms about the interventions and their impact upon individuals lives. Although literature was available regarding the side effects and the physiological impact of chemotherapy, radiotherapy and surgery on heterosexual women's sexuality and sexual health, this literature was not seen to be appropriate within the search inclusion criteria which reflected the aims of the study.

Lesbian and bisexual (LB) women specific studies

As only four studies were found it was seen to be important to examine each of these in depth. However, it has to be noted that for each of these studies Boehmer (2009), Mathews & Boehmer (unpublished), Boehmer & Timm et al (2012), there was the same leading or contributing author. Therefore, it has to be accepted that overall there are some similarities in the perspectives discussed.

Boehmer, Potter & Bowen (2009) aimed to review what is known about LB and women partnered women's (LBWPW) sexual functioning after cancer, to explore reasons why the sexual functioning may differ from heterosexual women and identify areas for further research. Unfortunately, similar to the current critical review, Boehmer, Potter & Bowen (2009) found little LBWPW specific literature, in fact they found 0 specific studies, and two studies where lesbians and heterosexual women were compared and where the psychosexual and relationship aspects were part of wider areas explored within the studies. This led to a discussion of the cancer related issues presented by or experienced by women with a lesbian

or bisexual identity. Boehmer, Potter & Bowen also discussed the findings of an unpublished research project which appeared to look specifically at sexual function of lesbian survivors of breast cancer and compared these findings to those of Fobair & O'Hanlon (2001) & Arena & Carver (2007).

From these three studies (two of which are non-LB specific) Boehmer et al (unpublished) draw some tentative conclusions namely, that LBWPW experience fewer sexual problems (better lubrication and orgasm), better body image and have more understanding /supportive partners than heterosexual women with breast cancer. However, these conclusion are made from very few studies with non-LBWPW specific research groups. In addition all of studies are from the USA (with its own set of LBWPW cultural norms), and furthermore the women in the studies were mostly European American, professionals in well paid jobs (and therefore may not be representative of the wider population of LBWPW).

Clearly building on these two studies Boehmer and her colleagues undertook and published two further specific studies. Firstly, Boehmer et al (2012) study utilised the conceptual model developed by Ganz et al (1999) to identify the factors of sexual function among LBWPW with breast cancer and compare these to LBWPW without cancer. This conceptual framework adopts a holistic approach to explore the multifaceted nature of female sexual function and satisfaction. Boehmer et al (2012) study recruited a convenience sample of women from various LGBT agencies, websites and targeted LGBT events, with the control group being recruited via advertisement's, support groups and websites. The inclusion criteria included women who had a history of breast cancer, from 1 – 10 years prior to study, women who were being treated with tamoxifen, anti - oestrogens or aromatase inhibitors, and those with recurrent disease. The study excluded women who had metastatic breast cancer. Whilst the authors acknowledged the importance of having 1 year free from treatment with radiotherapy or chemotherapy, they appear not to have taken account of the impact of the other treatment modalities on the women's sexual function (Baumgart & Nilsson et al, 2013). In addition, they failed to acknowledge the psychological impact of recurrent cancer and the effect this may have on both the individual women and their partners (Northouse & Dorris et al, 1995, Sarenmalm, Ohlen et al, 2007), which would influence the nature of their intimate and sexual relationship. The control group were age and partner status matched. The study used a variety of validated questionnaires to measure the various factors identified by Ganz et al (1999) within their conceptual framework. These included the Female Sexual Dysfunction Index, Hospital Anxiety and Depression Scale, Menopause Rating Scale, Self-esteem scale and the Dyadic Adjustment Scale. The statistical analysis undertaken were t test and linear regression for between group comparisons and chi squared tests and logistical regression for comparisons between variables. As the article did not provide details of the numbers of women

recruited therefore it was not possible to assess the appropriateness of the statistical analysis undertaken. This was seen as problematic especially in terms of the sample size required for linear and logical regression where large numbers would be required for the number of variables being examined (Denis & Hicks, 1999).

The control group demonstrated significantly higher levels of sexual attractiveness and significantly less menopausal symptoms than the cancer survivors. Overall, the LBWPW breast cancer survivors demonstrated lower levels of sexual attractiveness and dyadic cohesion together with higher levels of menopausal and urogenital symptoms which all contributed to lower levels of sexual frequency and satisfaction. The article did not provide details of the numbers of women recruited therefore it was not possible to assess the appropriateness of the statistical analysis undertaken. This was seen as problematic especially in terms of the sample size required for linear regression. These effects are very much in keeping with the results demonstrated by previous studies undertaken with heterosexual women with breast cancer and their partners (Hughes, 2008, Sadovsky et al, 2010, Melisko, Goldman & Rugo, 2010).

Secondly, Boehmer et al (2013) explored whether LBWPW who had been treated for breast cancer experienced greater levels of sexual dysfunction than LBWPW without breast cancer. The study was a case - control study involving a convenience sample of 85 women treated for breast cancer and 85 case control LBWPW without breast cancer, both partnered and un-partnered and utilised the female sexual function index (FSFI) questionnaire (amended for LBWPW by Boehmer et al, 2012) to assess the levels of sexual dysfunction and satisfaction. They amended the FSFI to safeguard sexually non active participants or clients from being scored as being sexually dysfunctional. Additionally, to make the language and assessment more applicable to LBWPW the wording of vaginal penetration was amended to accommodate vaginal penetration with any object (fingers, sex toys).

The results showed that the levels of overall sexual satisfaction did not differ between the two groups of women, however, the women who had experienced breast cancer demonstrated lower levels of sexual desire and had more difficulty achieving orgasm than the control group. This is very much in keeping with the findings of studies of heterosexual women survivors of breast cancer (Hughes, 2008, Sadovsky et al, 2010, Melisko, Goldman & Rugo, 2010). In addition, the FSFI, whilst a very useful tool for the practitioner to use for the assessment of female sexual function and dysfunction has previously been criticised and amended to suit the needs of particular client groups (Meyer- Bahlburgh & Dolezal, 2007).

Lesbian comparative group studies

Only two peer reviewed comparative research articles were found, Fobair & O'Hanlon et al (2001) recruited 246 women, who had a diagnosis and treatment of breast cancer of these 29 were lesbian women. These women formed part of a larger study looking at the psychosocial needs of heterosexual and lesbian women. The heterosexual women were recruited from a clinically located multicentre study of college educated women with breast cancer. Whilst the lesbian women were recruited from a non-clinical base, recruiting via existing LGBT organisations and newspapers.

The inclusion criteria included women with primary breast cancer diagnosed within the preceding 12 months who had completed their initial surgical intervention but who were still to undergo any further treatment with chemotherapy, radiotherapy or hormone therapy. This is seen as a weakness of the study, as the women were in early stages of their cancer experience and also had not encountered any potential impact on both their body image and sexual activity due to the adjunctive treatments. The study excluded women who had a metastatic spread, cancer recurrence or other major life shortening illnesses.

The study included a number of areas for examination, however, in terms of those relevant to this study the area of the impact on body image and sexual activity will be explored here. Fobair & O'Hanlon (2001) utilised two previously validated questionnaires to examine these areas. Firstly, they used the "Body image and Sexuality Scale for Women with Breast Cancer (BISS) designed for the study. The other questionnaire was the Sexual Activity Questionnaire (SAQ). In terms of analysis the study used six items to analyse their experiences before and since their breast cancer diagnosis and treatment in relation to the following. How comfortable the women had been, and were showing their bodies to other people, how comfortable the women had been, and were about their body weight and finally how satisfied the women found their sexual lives.

The results demonstrated that the lesbian women experienced less problems with their body image, were more comfortable showing their bodies to other people than their heterosexual counterparts. This was not however a predictor of better sexual functioning, in addition, these differences in body image were less statistically significant post breast cancer. Of those women who were not sexually active the study demonstrated that the lesbian women were more likely to be not interested in sex. Furthermore, there was a slight trend, but of weak statistical significance ($p=0.07$) that the heterosexual women experienced greater sexual satisfaction in their pre cancer lives.

Arena & Carver (2007) used combined postal questionnaires, consisting of various previously validated questionnaires to compare the experiences of 39 self-identified lesbian women and

39 heterosexual women who had a diagnosis of breast cancer, matched for age, ethnicity, stage of cancer and time since diagnosis. The heterosexual women were recruited as part of a clinical multicentre research study at centres based in south Florida. Whilst the lesbians were recruited from across the USA via recruitment flyers disseminated through physicians, women's networks and lesbian community resource centres. The recruitment strategy appears to have a few implications for the study, firstly the use of convenience sampling raises the question of potential selection bias by utilising self-selecting volunteer participants. In addition, it is unclear what, if any implications of utilising a nationwide sample of lesbians might be. It could be argued that the lesbians experiences regarding their relationships may be different based on their geographical location and environment – for example whether they lived in a rural or urban area.

The inclusion criteria included women with primary, early stage breast cancer, who were near to time of diagnosis to those who were 5 years post treatment. This is seen as a potential weakness in the study, as the experiences reported are likely to be different for the women dependent on where in their survivorship phase they were. The report did not state whether the women were still receiving any continuing treatment with tamoxifen, anti - oestrogens or aromatase inhibitors, which are known to impact on sexual interest and sexual satisfaction. The study excluded women who had a previous cancer, advanced breast cancer (beyond stage II) or had a history of hospitalized psychopathology.

The study included a number of areas for examination, however, in terms of those relevant to this study the areas concerning body image, relationship satisfaction, sexual disruption, sexual activity and psychosexual adjustment were relevant. Arena & Carver (2007) utilised several self-completed questionnaires to explore these areas, no information was provided about the response rate for these questionnaires, seen as a limitation of the study. Concern about the body /body image was measured by the validated 'Measure of Body Apperception' questionnaire (Carver & Pozo- Kaderman et al, 1998, Petronis & Carver et al, 2003). The relationship – related measures used the validated 'Quality of Marriage Index' (Norton, 1983) plus non - validated ad hoc items to measure the women's perceptions of partner reactions to diagnosis and treatment. Sexual disruption and activity were measured respectively by the sexual subscale of the validated 'Psychosocial Adjustment to illness- scale (PAIS) (Dergatis, 1975) and a non-validated tool. Whilst psychosexual adjustment used a validated tool (Carver & Pozo- Kaderman, 1998), one measure within this was of femininity, the scale had previously been used in a study of heterosexual women, so one might question its applicability to lesbian women, who may view femininity or being a woman differently.

The results demonstrated that there were no differences between the women in regards to their relationship satisfaction in terms of how bothered their partners were by their surgical

scar, how much affection, whether there was any increased friction or fighting or how their partners reacted to cancer threatening their partners life. Nor were there difference between the heterosexual and lesbian women with regards to their sexual satisfaction pre and post their cancer diagnosis and treatment. The heterosexual women did however, report more disruption to their sexual relationships since diagnosis and treatment than the lesbians. The lesbians had reported less frequent sexual activity prior to diagnosis and treatment (although this was not statistically significant), this may have contributed to them reporting less disruption in their sexual relationships post diagnosis and treatment. Perhaps to be expected - as lesbian relationships have been shown to be more egalitarian (Klinger, 1996) the heterosexual women reported greater partner sexual initiation both pre and post diagnosis and treatment. As with Fobair & O'Hanlon's (2001) study the lesbian women experienced less problems with their body image than their heterosexual counterparts.

In both studies the reason given for the difference in recruitment method as being due to the hidden nature of lesbians within a clinical setting (i.e. not known to the practitioners – highlighting again the problems that this hidden sexuality brings). However, recruiting via existing LGBT organisations and newspapers can potentially influence the recruitment from the wider lesbian and bisexual women's 'community' who may not access these sources of information.

All of the lesbian specific studies adopted quantitative research methods which did not give a sense of **how** the women and their partners had experienced and lived through their cancer 'journey/s' and how their relationship had been effected by the illness and treatments. For this study it was seen as essential to give these women a voice, to hear of their experiences and stories in so doing adding a clear human dimension to the information available to health care practitioners working in the cancer care. Hence, it was considered as appropriate to undertake some phenomenological interviews with lesbian and bisexual women and their partners who had been effected by breast, cervical, uterine or ovarian cancer. This will be presented as Chapters six and seven.

The literature confirmed the need for this study to give voice to the unheard stories and experiences of lesbian and bisexual women effected by cancer, and to provide the HCP's with an evidence base to guide their practice with the women in these essential areas. In light of the literature explored, pertaining to the preparedness of HCP's in recognising and addressing the specific needs of LGBT patients /clients, there was a need to consider cancer care practitioners and educators. Thus, the first phase of the journey was undertaken with an expert panel of senior practitioners and educators.

Extracts from reflective research journal and reflexive comments:

“As an educator, teacher and supervisor I was used to carrying out literature searches and assumed that in this study it would be relatively straightforward. I focused on checking that during searching and critiquing the available literature I explored widely – using appropriate professional search engines – medical, nursing, psychological, LGBT /homosexuality, social sciences. I formulated extraction grids that reflected the aims of the study, and utilised established systematic / critical review guidelines (RCN, Joanna Briggs, Cochrane) in the construction of the search, study extraction and critique. I was aware that the past sexuality in health care practice literature and background information needed to reflect the age range of potential patients that HCP would experience, rather than my own personal LGBT timeframe /history.”

*Whilst there are areas of commonality of experience I was aware that there are cultural differences that impact on studies, for instance **there are differences between the experiences of lesbians in the UK and USA (different histories and continuing experiences)**, and that initially the lesbian specific studies had all been all USA based.”*

The reflections that emerged as the research was identified and retrieved, reveal that it was at this point that the need for my study was confirmed and that

“It was sad to see how little had really changed in terms of ‘general sexuality in practice’ – couldn’t help feeling partly responsible for this, as I have been in healthcare education for many years. As I made so little difference??”

I had to accept that while I had worked locally and in some instances nationally, and personally was well known in the field, perhaps I should have disseminated my own work more widely.

Chapter Four: Journey Phase One (C)

The Expert Panel: Workshop and Questionnaire

Positionality: the role of facilitator

When commencing working with the various different groups of participants in the study it was necessary to review my position as an insider or outsider to the group i.e. the degree of my connection to the group I was 'studying' (Merriam & Johnson - Bailey et al, 2001, Bourke, 2014). In this instance the expert panel consisted of cancer educators and practitioners. I am a very experienced educator of healthcare practitioners including both medical and nursing practitioners, so in many respects the expert panel members 'peer'. However, I was 'working' in the capacity of a researcher facilitating their discussion and concerned with their experiences of caring for /working with a marginalised group of women in regards to sensitive areas of human experience. As the group consisted of very experienced practitioners and educators, I anticipated and looked forward to learning about expert accounts of excellence in practice. I was also aware of my own experiences and concern that I might encounter descriptions of experiencing homophobia within their health care practice and education and had carefully considered strategies to identify if or how this might 'shape' my interactions with the participants.

Introduction

The initial literature had confirmed the need for the study but also that there was very little contemporaneous information. Therefore, in the absence of this information and in order to develop the conceptual framework there was a need to seek the views of experts in cancer care and cancer education. As this was a study inspired by phenomenology it was necessary to consider which research methods could be used for this task. Within descriptive phenomenology inevitably the first choice would have been individual interviews, however, whilst allowing for provision of in depth of information, these would not allow participants to share and exchange ideas. Thus inhibiting the expansion of the depth and scope of the data/information, these were therefore not appropriate. A further technique considered was the nominal group technique (NCT), extensively used to explore consumer and stakeholder views. This has classically a four stage process, namely silent generation (of ideas), a group round robin, clarification and ranking (Mcmillan & King et al, 2016). The technique is useful when the generation of a large number of ideas and the potential for creative decision making and participant satisfaction is required (Totikidis, 2010). As these were not the aims of the

'consultation' with, and seeking the opinions of, the expert practitioners and educators the NCT approach was not seen to be appropriate.

One method which could be modified and adapted for use in a phenomenological study was the Delphi technique, as some of the stages within the method can be qualitative (Okoli & Pawlowski, 2004, Landetta, 2005, Brady, 2015). The Delphi method was originally formulated and used by the RAND corporation in the USA in the 1950's and 1960's as a method of collecting and synthesising expert opinion, without the difficulties inherent in expert group based activities (Gordan and Pease (2006). The Delphi method can be viewed as a series of iterations or rounds in which every participant works through a questionnaire, which is returned to the researcher /group co – coordinator, who collates, edits and returns to the participants a summation of views /opinions of the whole group, together with an individual summary statement. This feedback process allows and encourages the participants to reassess their judgements and opinions about the information provided in each of the iterations /rounds. A traditional Delphi method would use three or four iterations /rounds, until a consensus is reached (Okoli & Pawlowski, 2004, Gordan and Pease, 2006, Geist, 2010). The Delphi technique is a widely used and accepted method for gathering information from participants within their field of expertise (Avella, 2016), it was therefore considered for this phase of the study, as Landeta (2005) and Brady (2015) suggested that this is a useful social sciences technique that aims to obtain a reliable group opinion using a group of experts. Further, Gordan and Pease (2006) suggest that a Delphi approach can generate ideas, both those that seek a consensus and those that do not. As the aim of the investigation with the 'experts' was to explore and discuss key issues in order to meet the aims given below, a full Delphi method was not seen to be an appropriate research method, as not all stages fit within phenomenology. Instead, a modified Delphi method was adopted with two of the underlying principles of a Delphi approach as outlined by Landeta (2005) adhered to. Firstly, the experts were consulted on three occasions (including workshops and an online questionnaire). Secondly, to ensure that irrelevant information was eliminated, there was controlled feedback with exchange of information provided via myself as study group co-ordinator seen as a pivotal role within the Delphi method (Hsu & Sandford, 2007, Avella, 2016).

The **overall aim** was to ascertain the knowledge, attitudes and experiences of expert cancer practitioners and educators in relation to assessing and addressing the sexuality and sexual health needs of lesbian and bisexual women with cancer.

For This Data Set The Aim Was To:

Identify and explore the following:

- Attitudes of expert doctors, nurses and health care professionals towards lesbian and bisexual patients.
- Appropriateness of cancer services for lesbian and bisexual women.
- Assessment and interventions undertaken by the experts with lesbian and bisexual women and their partners in regards to their sexuality and sexual health.
- How these issues are addressed/ covered in any educational programmes they are involved in or responsible for with healthcare practice students.

Step one: Delphi rounds one and two: The researcher facilitated workshop

The workshop took place at an international cancer educator's conference held in Poland, the choice was made as it would provide access to senior medical, nursing and healthcare cancer educators and clinicians. The conference workshop was not designed for large numbers of participants, rather it aimed to attract very senior cancer expertise from a range of countries to act as an expert panel. Participant information sheets and consent forms were provided to the conference attenders at the commencement of the conference. This enabled the potential participants the opportunity make an informed choice about attending the workshop and completing the questionnaire.

Sample

Denzin & Lincoln (2011) suggest that a good research participant is one who has knowledge and experience required. Patton (1990) further suggests that the logic and power behind purposeful selection of participants is that they should be 'information rich'. Whilst Welman & Kruger (1999) considered purposive sampling the most important kind of non-probability sampling, as it utilises individuals who have had experience of the phenomenon under investigation. The main aim of purposive sampling is to focus on particular characteristics of the population of interest, which will best answer the research question/s. In this case homogeneous purposive sampling was used, as this element of the study required a sample who shared the same (or similar) traits, in this case very experienced cancer practitioners and educators. Purposive sampling has the advantage of ensuring a balanced sample when multiple participants are selected. However, the sample may not be easily defensible as representative of the population due to potential subjectivity of the researcher (Black, 1999, Bryman, 2008). The issue of non-generalisability of the findings was not viewed as

detrimental, as the aim of this part of the study was to seek the views and experiences of experienced practitioners as a starting point for further discussion and exploration with patients, partners and other healthcare practitioners at a later phase of the study. As the aim of the workshop and questionnaire was to gain information about the views and experiences of expert cancer practitioners and educators the conference provided a purposive sample of experts. Although there is no definitive sample size for a Delphi technique process, it has argued that a sample of approximately fifteen participants is appropriate (Linstone & Turoff, 2002, Macmillan, King & Tully, 2016). The workshop was attended by 16 participants appropriate for a modified Delphi. Table (1) below demonstrates both the wide geographical spread and areas of practice expertise of the workshop participants. Despite the participants countries of origin no language difficulties were experienced.

	Country	Professional practice area
1	UK	Gynaecology oncologist
2	UK	Medical anthropologist
3	UK	Nurse & senior lecturer in cancer care
4	UK	Professor in Community Health Nursing
5	USA	Clinical psychologist – cancer care
6	USA	Nurse, Doctor & oncologist
7	USA	Doctor, oncologist & academic
8	USA	Doctor, oncologist & researcher
9	France	Professor of oncology
10	Netherlands	Breast surgeon & oncologist
11	Netherlands	Healthcare practitioner & researcher
12	Australia	Nurse & senior lecturer in cancer care
13	Austria	Social worker – cancer care
14	Poland	General cancer surgeon
15	Poland	Radiologist
16	Greece	General surgeon

Table (1): Workshop participant's counties and practice roles.

Whilst in a traditional Delphi method there would have been information regarding the subject provided to participants ahead of the workshop, although this was volunteered it wasn't possible to send out to all participants (due to conference administrative reasons). Therefore the workshop was structured in two parts (these constituted the 1st and 2nd Delphi rounds). Firstly, in order to be able to understand the specific differences presented when working with lesbian and bisexual women it was important that the workshop participants had an understanding of the history surrounding homosexuality, which led to the hidden nature of gay and lesbian relationships. Thus, the starting point was an overview of the global historical and legislative background to homosexuality. This was followed by a facilitated discussion around the myths and realities of lesbian identity and sexual behaviours. This allowed a flow into discussion pertaining to the similarities and differences in perceived and actual behaviours.

Having 'set the scene' the workshop then progressed to a presentation of a critical review of the literature pertaining to the effects of female and reproductive cancers on the sexuality and sexual health of both heterosexual and sexual minority women.

The workshop then moved into three facilitated multi-disciplinary group work for further in-depth exploration and discussion of the key issues emerging from the literature and 1st Delphi round namely:

- Do you address the sexuality and sexual health issues of your cancer patients in practice? If so, how do you do this?
- Taking this further, do you do this with patients who are lesbian or bisexual? Would you know how to facilitate this?
- How are these issues addressed /covered in your educational programmes with students?
- What (if any) are the barriers to doing the above?

In line with Delphi the workshop concluded with detailed feedback and discussion of the group work, together with a presentation and discussion of interventions (both environmental and practitioner led) which would be useful for addressing the needs of lesbian and bisexual women in regards to their sexuality and sexual health in cancer care settings. See Appendix five for workshop abstract. The one and half hour workshop was conducted in a setting which facilitated private group discussions. The decision was made not to audio-record the workshop to safeguard confidentiality and anonymity.

Data collection 1: Field notes

Field notes are an established method of observing a culture, setting, or social situation this includes verbal and non-verbal communication (Lofland & Lofland, 1995, Wolfinger, 2002, Burgess, 2006) and hence were taken during the workshop to remember and record the behaviours, events and attitudes shown by the participants. In keeping with the principles of phenomenology the field notes and observations described and identified the participant's experiences. The research aims and study design provided the theoretical criteria for what was recorded. The field notes taken during the workshop were principally observational notes, these focussed on the following:

- The context, history, physical setting and environment.
- Number of participants and key individuals.
- Activities taking place.
- Significant events, origins and consequences.

- Participant's perspectives and meanings.
- Group /social roles and patterns of order (group dynamics).

Continuing the method advocated by Lofland & Lofland (1995) were used to augment the analysis of the extent or not that consensus was reached on key issues. I attempted to derive meaning from the workshop observation by completion of theoretical notes. This was undertaken through thinking and reflecting on the experience. As this was a phenomenological adaptation throughout I needed to 'account' for myself through reflexivity and reflecting back to previous work on the topic. Here the self-reflection and positionality undertaken and written at the beginning of the study proved invaluable as it was essential to check I had not allowed my knowledge and expertise to force consensus on any key issue in Delphi rounds 1 and 2.

Structuring the observations in this manner allowed for ease of analysis, the method of which is discussed in the next section. Furthermore, the use of my research diary proved to be an important source of reflection and a 'space' to make sense of the occurrences both within the workshop, and out of workshop discussions with workshop participants. This was especially important, as several of the participants clearly felt uncomfortable discussing issues within the workshop but felt more able to on a private one to one basis.

Data analysis 1: Delphi rounds one and two:

The workshop notes and research journal were treated as text and were subjected to a modified phenomenological analysis which used only phenomenological reduction (epoche') (Lofland, Snow & Anderson et al, 2005) analysing each workshop activity sequentially. Interpretation of the analysis of the process field notes was supported by the reflective notes and research journal as outlined above, to give meaning to the analysis. Tables (2) and (3) offer extracts from the analysis including the emerging themes which are presented in Table (4).

Table (2) - Extract of analysis – Expert panel: workshop and group work: data extraction and coding

Code	Description of code	Where in field notes/workshop	Original Transcript	Reflective initial comments
1	Lack of knowledge of impact on sexuality of cancer & treatments.	Workshop section 3.	No problems with listening but still some looking wary as this included information that the next section would be interactive. "Looking at the sexual side of treatments isn't something I know much about – I'm there to cure the patient!"	Some expressed a lack of knowledge regarding the impact on sexuality etc of cancer & treatments (very surprising given the nature of their senior/experienced roles in cancer care & cancer related education).

2	Participants uncomfortable with topic/s.	<p>Workshop section 1.</p> <p>Workshop section 4.</p> <p>Workshop section 6 – sexual language & sexual acts exercise.</p>	<p>Interest in workshop but some shuffling among participants including younger groups, some looking a bit anxious ,</p> <p>several people were clearly becoming uncomfortable and avoiding eye contact with each other, time spent staring at the tables.</p> <p>This discussion of activities caused the real discomfort with total avoidance of eye contact amongst some of group, would not even meet eyes across the room. Some support for discussion from mental health colleague but comments needed to be requested repeatedly and prompts given. Participants not keen to work in groups or pairs, so discussion made general, but still anything but easy.</p> <p>Also raised continuum of paraphilia and other issues but to observer this seemed almost as diversionary tactic as one remove from something they saw as too close.</p> <p>"I don't feel comfortable talking about sexual things with my patients, or other people really. I guess it's the way I was brought up – things like that were not discussed."</p>	<p>Initial unease of the participants possibly about the LGBT specifics.</p> <p>The degree of discomfort demonstrated didn't appear to be only to do with the discussion regarding lesbian sex but reflected a more general discomfort with discussing sex per se. Rather disappointing given that these were mature & senior nature of the participants. It really made me wonder how comfortable they would be discussing sexuality etc issues with their patients & partners and also about teaching HCP students about these issues. Really reflects all of the previous work done around HCP being uncomfortable talking about & addressing sexuality with their patients.</p>
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Table (3) - Extract of analysis – Expert panel: workshop and group work: theme generation

Description of code	Where in field notes/workshop	Original Transcript	Reflective comments initial	Emerging theme
Lack of knowledge of impact on sexuality of cancer & treatments.	Workshop section 3.	<p>No problems with listening but still some looking wary as this included information that the next section would be interactive</p> <p>"Looking at the sexual side of treatments isn't something I know much about – I'm there to cure the patient!"</p>	Some expressed a lack of knowledge regarding the impact on sexuality etc of cancer & treatments (very surprising given the nature of their senior/experienced roles in cancer care & cancer related education).	Lack of knowledge of impact on sexuality of cancer & treatments (generally & LBW).
Participants uncomfortable with topic/s	<p>Workshop section 1.</p> <p>Workshop section 4.</p>	<p>Interest in workshop but some shuffling among participants including younger groups, some looking a bit anxious.</p> <p>Several people were clearly becoming uncomfortable and avoiding eye contact with each other, time spent staring at the tables.</p>	<p>Initial unease of the participants possibly about the LGBT specifics.</p> <p>The degree of discomfort demonstrated didn't appear to</p>	Practitioners unease discussing and exploring sexuality generally and LBW c/o cancer.

	Workshop section 6 – sexual language & sexual acts exercise.	<p>This discussion of activities caused the real discomfort with total avoidance of eye contact amongst some of group, would not even meet eyes across the room. Some support for discussion from mental health colleague but comments needed to be requested repeatedly and prompts given. Participants not keen to work in groups or pairs, so discussion made general, but still anything but easy. Also raised continuum of paraphilia and other issues but to observe this seemed almost as diversionary tactic as one remove from something they saw as too close.</p> <p>“I don’t feel comfortable talking about sexual things with my patients, or other people really. I guess it’s the way I was brought up – things like that were not discussed.”</p>	only to do with the discussion regarding lesbian sex but reflected a more general discomfort with discussing sex per se. Rather disappointing given that these were mature & senior nature of the participants. It really made me wonder how comfortable they would be discussing sexuality etc issues with their patients & partners and also about teaching HCP students about these issues. Really reflects all of the previous work done around HCP being uncomfortable talking about & addressing sexuality with their patients.	
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Findings: The Context of Delphi Round One and Two

Although the two rounds were carried out initial data analysis showed there was little difference in the findings from the data sets, therefore these will be presented as one.

During the analysis of the workshop I returned to the context of the workshop and transcripts to check for bias. In keeping with phenomenological analysis no priority order was given to the themes generated, no one theme being seen as more important than any other. The workshop produced a wealth of information and generated four main themes identified in Table (4) below each of these themes will be explored in the following section.

Lack of knowledge of the impact on sexuality and relationships of cancer and treatments - generally and Lesbian & Bisexual Women (LBW).
Practitioners unease discussing and exploring sexuality generally and LBW.
Practitioners discomfort and lack of knowledge with regards to LBW.
Implications for practice and education.

Table (4) - Expert panel workshop themes

Lack of knowledge of the impact on sexuality of cancer and treatments (generally and Lesbian and Bisexual Women)

A number of the participants expressed a lack of knowledge of how cancer and cancer treatments can impact upon heterosexual individuals and couples sexuality, relationships and intimacy. This being even more evident when the discussion moved on to the impact on lesbian and bisexual women.

(Reflective research journal entry: Recorded participant statement).

"Looking at the sexual side of treatments isn't something I know much about – I'm there to cure the patient!"

"I can't understand the relevance of sexuality – are we going to talk about HIV?"

(Workshop field notes).

"Participants appeared OK with topic, some expressed a lack of knowledge regarding the impact on sexuality etc of cancer & treatments."

"All professionals should be able and willing to talk about relationships with patients, and if partner is another women this should be acknowledged and discussed with partner fully involved in care planning – but they /the group don't know how to do this in their practice."

The general lack of knowledge was very surprising given that the participants were, on the whole, experienced cancer practitioners and educators. As the literature review for this study demonstrated, the impact on these areas of heterosexual individuals lives have been recognised for many years. It was therefore surprising that these senior practitioners appeared to be unaware of this information. This lack of knowledge could be seen to reflect the medical model of practice, which the majority of the participants adopted, which places sexuality and sexual health together, the focus being on sexual health in terms of Sexually transmitted infection (STI) prevention.

(Reflective research journal entry: researcher).

"I was very surprised by that many of the participants expressed a lack of knowledge regarding the impact on sexuality etc. of cancer & treatments (very surprising given the nature of their senior /experienced roles in cancer care & cancer related education). This lack of understanding etc. became even clearer when the workshop moved onto the lesbian & bisexual women specifics. It was more worrying as many of the participants are responsible at least in part for the education of future doctors and nurses."

Practitioners unease discussing and exploring sexuality generally and lesbian and bisexual women

The degree of discomfort demonstrated by participants when discussing sex and sexuality was quite astonishing and did not appear to be only with regards to the discussion regarding lesbian sex. Instead it reflected a more general discomfort with discussing sex per se.

(Reflective research journal entry: recorded participant statement).

"I don't feel comfortable talking about sexual things with my patients, or other people really. I guess it's the way I was brought up – things like that were not discussed."

(Reflective research journal entry: researcher).

"The discomfort in the room was almost palpable, what was the difficulty here? I couldn't believe that such senior people were so ill at ease with talking about sexuality generally – this was like teaching post - reg nurses 15 years ago! Have things really not progressed in that time??"

This was very disappointing given that the participants were mature and senior specialist practitioners, raising several important questions. Firstly, how comfortable the participants would be discussing sexuality, relationships and intimacy issues with their patients and partners. What do they do and how do they work with their patients in regards to these areas of their patients' lives. Secondly, it raised questions about how comfortable **and** competent the participants (who were key and very senior practitioners) are in teaching health care practice students about these issues, as all of the participants have an education as well as clinical role. The workshop / expert panel had been something they had chosen to attend, it appeared that they were comfortable with theoretically exploring the topic areas. However, they had failed to understand that a phenomenological workshop required that they look at themselves (knowledge, beliefs and attitudes), together with their practice. Thus they had not anticipated the feelings of discomfort they experienced. It has long been recognised that a prerequisite for teaching about and practicing in regards to sexuality and sexual health is practitioner self-awareness (Webb, 1985, Webb & Askham, 1987, Olsson, Berglund & Larsson, 2012). This was therefore a very worrying issue when considering the education of

the next generation(s) of healthcare practitioners, confirming the need for the development of the conceptual framework.

The findings here reflect the previous work explored in the supporting literature with regards to healthcare practitioners being uncomfortable talking about and addressing sexuality with their patients. The greater level of discomfort was apparent when discussing Lesbian and Bisexual Women (LBW) specific elements within the workshop, this links to the next theme.

Practitioners discomfort and lack of knowledge with regards to lesbian and bisexual women

Many of the participants showed a lack of understanding about sexuality and specifically about lesbian and bisexual sexual orientation and lifestyles. There appeared to be some surprise from participants that any woman they meet may be a lesbian or bisexual woman.

(Reflective research journal: recorded participant statement).

"I don't see why these women (LB) should be treated any differently from all my other patients. They have cancer and it needs to be treated – how important is who they share a bed with and what they do there to this? I don't get it!"

"Our society is more open these days, but I don't know much about other people's lifestyles and I don't think it's important for me to know as their doctor"

(Workshop field notes).

"No one had considered that sexuality is only one aspect – several people were clearly becoming uncomfortable and avoiding eye contact with each other, time spent staring at the tables – seemed to be a belief that people could choose sexuality some surprise that it could be 'part of normal life' "

"This discussion of activities caused the real discomfort with total avoidance of eye contact amongst some of group, would not even meet eyes across the room."

"Assumptions that all women 'are the same' leads to lack of support and help for both patient and partner."

(Reflective research journal entry: researcher).

"I was so surprised by the lack of knowledge these practitioners had, they had clearly 'bought into' the stereotypes around lesbians – I expect they thought they could 'spot a dyke' a mile off! I really feel for their patients, if this is how blinkered their views are."

This appears to reflect the research around heteronormative behaviour, encountered in practice settings as well as society in general (Walls, 2008, Morrison & Dinkel, 2012). This heteronormative stance fails to recognise that there may be differences in life experiences of and societal attitudes towards lesbian and bisexual women from their heterosexual counterparts. Linked to this theme was the participant's lack of knowledge of LGBT history,

religious and societal attitudes and legislation. An issue arising from this lack of knowledge is the practitioner's awareness of patient's psychosocial backgrounds and circumstances and how these can impact upon the patients' health and wellbeing. In particular the impact on older lesbian and bisexual women who may have lived through times when their sexuality needed to remain hidden, impacting on their mental health, possibly mediated through minority stress (Myers, 2001, Fish, 2010).

As stated in the previous section the majority of the participants demonstrated a greater uneasiness and discomfort when the workshop moved on from how they address sexuality with patients to the more LBW elements of the workshop. There were clear differences in the level of understanding, comfort talking about and considering lesbian sexual behaviour between participants from Western Europe and North America and those from Eastern Europe or more 'traditional/conservative' countries (MacKay, 2010). Some participants expressed the false belief that lesbians can't have 'real sex' because of a lack of a penis, allied to this was the belief that lesbians were not at risk of acquiring STI's as they didn't have 'real sex'.

(Workshop field notes).

"One suggested that there is a belief that although they can be 'close' lesbian women 'cannot have intercourse as they have no penis' "

"Also raised was the belief some had found that STIs could not be transmitted as 'traditional' intercourse did not take place."

The levels of discomfort and these inaccurate beliefs are seen as very worrying for a number of reasons. Firstly, is the impact on the practitioner – patient interaction/relationship of the practitioners own background, beliefs and life experiences. Especially where the practitioner is not able to recognise and acknowledge the differences in these which exist between themselves and their patients or where the practitioner's beliefs are so ingrained and at odds with those of the patient. Secondly, from a public health perspective this lack of knowledge (especially pertaining to STI transmission) is very worrying, being dangerous and potentially places patients at risk. Furthermore, it perpetuates the myth that lesbians don't need to have cervical screening as they can't become infected with the human papilloma virus (Zaritsky & Dibble, 2010). This fails to recognise that many lesbians do have sexual intercourse with men at some point in their lives, whilst by definition the bisexual women will also have done so. By perpetuating the myth / false belief the practitioners are putting these women at greater risk of a late diagnosis of cervical cancer, with the greater burden of morbidity and mortality this carries.

Implications for Practice and Education: Reflections on Delphi Round One and Two

The workshop identified several issues in regards to the participants practice, both clinical and educational. Firstly, they felt that professionals should be able and willing to discuss sexuality and relationships with their patients and that if the partner of a woman was of the same sex that they should be included in care planning throughout the diagnosis and treatment periods. However, when asked to say how they would do this they were less able to do so. This clearly has implications for practice, as the participants, although willing to be inclusive did not possess the knowledge and skills to do so. Furthermore, as educators of future practitioners, they would struggle to teach and empower their students to include sexuality and relationships within their practice and for this practice to be LGBT inclusive.

Several participants talked about the need to treat all women in the same way, seeing this as being non-judgmental and inclusive. However, as alluded to earlier, the use of heteronormative practice does not recognise the potential impact on lesbian and bisexual women of living as part of a minority group in a predominately heterosexual society. The concept of minority stress has been recognised as one of the many social determinants of health (Meyer, 1995, Meyer, 2005) with many studies outlining the negative impact on mental health and wellbeing of marginalised groups. The link between minority stress and unhealthy lifestyle behaviours such as excessive alcohol and smoking has been identified within the LGBT community (Meyer, 1995, Meyer, 2005). As identified in the literature review, it has been shown that lesbians may be at higher risk of cancers, such as breast cancer because of their high levels of alcohol consumption and smoking. It is therefore suggested that by working from a heteronormative model the participants are failing to fulfil their public health / health education role with their patients who are lesbian or bisexual women.

The participants also identified that they believed that there was a lack of education with regards to sexuality and LGBT health in pre-qualifying education programmes, both medical and nursing education. They suggested that this education and training needs to be reviewed and changes made. However, given the previously identified issues with the participant's own levels of knowledge and comfort with discussing sexuality and relationships with patients together with their clear discomfort when talking about the lesbian specifics it is questionable whether they would feel adequately prepared to undertake this education. One suggestion was made to include within the education the use of standardised assessment tools which include sexuality. Furthermore, that students need to be taught how to question without causing distress, anxiety and /or resentment. It is suggested that these suggestions should be extended to all practitioners, whether pre-qualifying or post-qualifying.

Allied to the previous sections is the need for practitioners to recognise their own limitations in regards to discussing sexuality and relationships with their patients. Professionals who find it difficult to raise the subjects tend to avoid them altogether (Zeng, Liu & Loke, 2011), but there is a need to accept their responsibility to assess and identify any care requirements in this area and then make the necessary referral. Regardless of sexuality all patients should be treated equally, if staff feel unable to raise the subject or cope with this issue they should identify a colleague who can carry out the discussion with the patient.

The final issue identified in relation to practice was the notion of **seeing patients as people and not just a person with cancer**. This was highlighted by the workshop experience of a junior participant, who said that they felt uncomfortable during the workshop. When her mentor pointed out that she needed to reflect on the workshop using her experience that day as a baseline for how patients might feel and that this might well change how she approached them, she admitted that she had never before thought about how patients undergoing chemotherapy or disfiguring surgery might feel when faced with a young and attractive doctor clearly in the peak of health. The mentor suggested that this demonstrated the impact on the patient, of the professional's response. This highlights the importance of the professional having a good sense of self that includes self-awareness and an awareness of how they may be perceived by patients. Only when they recognise their own role and position, can they develop an empathetic understanding of their patient's lives and experiences, rather than seeing the patient as an illness requiring treatment.

Data collection 2: Delphi round three: Questionnaire

Although the participants were from many countries, to check that they were not an atypical group the use of an online questionnaire was viewed as an appropriate method to widen out the expert group membership. The conference organisers offered to send the questionnaire to senior members of their association membership (across both Europe and North America) who had not been present at the conference. Following approval by the faculty ethics committee, this was undertaken via Bristol online surveys. Consent was provided by completion of the questionnaire, whilst anonymity was safeguarded by the unique URL used for the survey.

The questionnaire needed to be descriptive and exploratory, aimed at identifying knowledge, attitudes and experiences of practitioners in regards to sexuality and sexual health issues in cancer care and education in general and specifically with regards to LBW (Sim and Wright, 2000). It consisted of a mix of closed questions (using Likert scales) and open-ended questions for respondents to explain their answers. As with any research method, the use of questionnaires present the researcher with both advantages and disadvantages, (De Vaus,

2002, Bryman 2012). Questionnaires are a useful tool where the intention is to gather straightforward information relating to people's behaviour and to look at the basic attitudes of a group of people relating to a particular issue (Oppenheim, 1992), in this case attitudes towards sexuality and sexual health generally and specifically related to LGBT patients (Oppenheim, 1992). The advantages of questionnaires include being able to contact a large number of people at relatively low cost (in the case of this study via Bristol Online Surveys at no cost to either researcher or participant), easy to reach participants who are spread across a wide geographical area (for this study access to expert practitioners and educators from Europe and North America). In addition, the questionnaire afforded respondents anonymity and the opportunity to complete the questionnaire in their own time – important when asking busy professionals to complete a questionnaire about sensitive issues. Furthermore, as with other computer mediated communication methods, the use of the online questionnaire was seen as an advantageous method of collecting data about sensitive topics (Elmir et al, 2011). The disadvantages of questionnaire use include having little control over who completes them, nor can the responses be checked for truthfulness, which can lead to bias, and the need to keep the questionnaire short to avoid the respondent becoming bored and not completing all of the questions). The major disadvantage is the problem of potential low response rates (Bryman, 2012). However it was hoped that the ease of use of Bristol online would increase response rates.

Whilst the use of the online medium was advantageous in attempting to reach more participants, it also required investigation into the use of online questionnaires as an appropriate methodology. The advantage of this type of online questionnaire is that it can be used for both quantitative and qualitative surveys. Fielding, Lee & Blank (2008) and Silvo & Saunders et al (2006) offered guidance, in what is still a relatively new approach to questionnaire. To encourage the completion of the questionnaire an adequate time frame was allowed and a reminder was built into the unique web link (Ogier, 2005, Nulty, 2008). In the last three years, since this element of the study was undertaken there has been an increase in numbers of studies using online methods of data collection. At the time this was carried out however, their use was new to the ethics committee – which carefully considered the ethics of its application for use in a sensitive and contentious area.

Sample

As stated previously the use of the online questionnaire was to check that the experts participating in the workshop were not atypical, at the request of the conference organisers a predetermined sample of additional expert practitioners was added. These consisted of the senior members from the two cancer organisations involved in organising the conference from

across both Europe and North America. Therefore, a sample of an additional 20 participants was sought.

Data analysis

The questionnaires were subjected to qualitative descriptive analysis to produce descriptive statistics. These together with the key points from the workshop previously outlined formed the expert's opinion which had been sought.

Questionnaire Findings

Tables (5) and (6) provide information on the geographic and practice backgrounds of those completing the questionnaire. As this was a qualitative questionnaire the number of response $n = 8$ or 40 percent was seen as adequate. The results from the questionnaires taken together with the perceptions and experiences gained from the workshop were combined. Collectively, these give a robust picture of the views, experiences and practices of these expert practitioners and educators.

Additionally, the 40 percent response rate is in line with online survey response rates found to be satisfactory by previous researchers (Sivo & Saunders et al, 2006). Moreover, Vehovar & Manfreda (2008) have shown online questionnaires /surveys to be on average 20 -30% lower than standard mail questionnaire /survey responses. Sivo & Saunders et al (2006) further demonstrated that highly educated practitioners, such as those surveyed are less likely to complete questionnaires of whatever nature. As qualitative data questionnaire results they were not intended to be generalizable, they do however provide the snap shot of the expert educators and practitioner's experiences, and together with the conference workshop observations make some recommendations for education and practice possible.

Country of Practice	Number
USA	2
Canada	1
Poland	1
Netherlands	2
Australia	2

Table (5): Questionnaire participant's geographic backgrounds.

Healthcare background	Number
Doctor	2
Medical education	1
Nurse	1
Specialist nurse	1
Nurse/healthcare educator	1
Other	2

Table (6): Questionnaire participant's practice background.

Table (7) shows a similar pattern with both practitioners and patients not raising the subjects of sexuality and sexual health in the consultation. This mirrors Haboubi & Lincoln (2003), Morris & Magnan, et al (2005) and Saunamaki, Andersson & Engstrom (2010) work which demonstrated that patients expect HCP's to raise the subject, whilst the practitioners expect patients to ask the questions which therefore this perpetuates the 'veil of silence' around the issues.

It was heartening that some of the practitioners stated that they ask patients, however looking at what support they offer in these 2 different areas i.e. sexuality and sexual health several of those offering support stated they would give guidance and information about STI's and contraception.

(Expert panel questionnaire).

"I provide information about contraception and the risk of sexual infections – especially if the woman is going to have chemotherapy, you need to prevent pregnancy and risk to the husband from the treatment."

(EP participant 5)

Demonstrating a biomedical rather than a holistic approach to care in these areas, as previously demonstrated by Dixon & Regan et al (2002) & Solursh & Ernst et al (2003) and possibly a result of some of the participant's medical background.

In terms of asking about intimate relationships it was perhaps unsurprising the majority of practitioners stated that they didn't ask or broach the area with their patients. This is seen to reflect HCP's not seeing this as a legitimate area to their practice (De Vocht et al, 2011).

	Yes Number	No Number
Ask about sexuality	3	5
Ask about sexual health	3	5
Ask about intimate relationships	2	6
Do clients/patients ever raise the subject of sexuality with you?	2	6
Do your clients/patients ever raise the subject of sexual health with you?	2	6
Do you deal with these yourself?	2	6
Ask them to see someone else?	3	4 1 N/A)
If so who?	More senior nurse, doctor, social worker, clinical psychologist.	

Table (7): Questionnaire participant's – asking patients about sexuality, sexual health and intimacy.

How comfortable to do you feel about asking questions about sexuality and sexual health with your clients/patients?	Number
Very comfortable	0
Comfortable	2
Uncomfortable	4
Very uncomfortable	0

Table (8): Questionnaire participant's - levels of comfort asking patients about sexuality, sexual health and intimacy.

When looking at the levels of comfort with asking patients about the issues (Table 8) it was apparent that the practitioners were on the whole not comfortable asking their patients questions in relation to their sexuality and sexual health. Previous research in the area of sexuality in patient care has identified that one of the reasons practitioners identified for not addressing patient needs in this area was their own level of discomfort in dealing with these personal issues (Harboubi & Lincoln, 2003 & Saunamaki, Andersson & Engstrom, 2010). Those practitioners who were uncomfortable with the topic area however, said they would ask for the patients to be seen by someone else either a more senior colleague, doctor, social worker or clinical psychologist.

Moving on to asking patients about their sexual orientation (Tables 9 and 10) the answers given were rather confused. The majority stated they did not asked their patients, however more stated that they feel comfortable doing so. Three respondents said they feel uncomfortable or very uncomfortable asking, whilst the remainder stated either that they didn't

ask or that they feel more confident because of the changing perceptions of society. It is suggested that this is contributory factor for those who feel comfortable in asking patients about sexual orientation.

Within the above do you ever ask about sexual orientation?	Number
Yes	2
No	6

Table (9): Questionnaire participant's – asking patients about their sexual orientation.

If you ask how comfortable to do you feel about doing so?	Number
Very comfortable	0
Comfortable	3
Uncomfortable	1
Very uncomfortable	2
Other	2 (don't ask, more confident or changing perceptions of society.)

Table (10): Questionnaire participants – level of comfort asking patients about their sexual orientation.

When asked what would prevent them from asking patients about their sexual orientation, again there was a mixed response. Which did however demonstrate again the lack of holistic perspective from those with a medical background.

(Expert panel questionnaire)

“Not relevant to differential diagnosis” (EP participant 5)

“Not relevant to my part of the trajectory”(EP participant 2)

“Probably not – although I would be mindful of how I approached the subject” (EP participant 1)

As discussed earlier previous research and literature has identified that LBW experience or fear experiencing negative attitudes from HCP, impacting upon their willingness to engage with important health interventions e.g. cervical and breast screening (Hunt & Dick,2008, DH,2010, Tracey et al,2010), and fear of either being judged negatively or their partners being excluded from decision making or care opportunities leading to unnecessary distress at a stressful /difficult time for both the patient and their partner (Roberts & Patsdaughter,2004, Tracey et al, 2010, DH,2010, White & Boehmer,2012). It is however suggested that there may be several contributory factors at play here. Firstly, the HCP's general discomfort when addressing sexuality related issues – as stated often relates to a lack of their own sexual self - awareness, a perceived lack of knowledge and skills, together with a lack of confidence in

utilising the skills they have through fear of ‘offending’ the patient or ‘opening a can of worms’ which they won’t know how to manage (Saunmaki et al, 2010). A further element is believed to be the patients and partners own internalised homophobia Williamson (2000), leading them to expect negatively judgmental care.

When exploring how the practitioners supported their patients in regards to sexuality, sexual health and intimacy number stated that this wasn’t something they would routinely offer. With one stating that:

(Expert panel questionnaire)
“ I didn’t ask my patients to see anyone”
(EP participant 2)

Where support was offered it was by the provision of information especially related to STI’s or referral to sexual health clinics or referral to another practitioner

(Expert panel questionnaire)
“Guidance, information about STD’s etc. (proctology: STD/HPV) (EP participant 6)
“Guidance, info (e.g. sexuality with ostomy etc) – by another team member”
(EP participant 7)
“ Referral to nurse specialist, urologist or clinical psychologist” (EP participant 1)

Chapter Summary and Conclusion

The workshop and online questionnaire constituted the first phase of the modified Delphi approach. As such they represent the expert opinion and cannot necessarily be regarded as representative, however they do identify several areas of concern. Firstly, the lack of knowledge of the impact of cancer and treatments on women’s sexuality. Secondly, the practitioners unease and discomfort with discussing and sexuality generally and with lesbian and bisexual women. Finally, the practitioners discomfort and lack of knowledge with regards to lesbian and bisexual women (lifestyles and relationships). This reaffirmed the need for an in depth study in this field.

Reflective research journal extract and reflexive comments

The whole expert panel workshop had been a shock, instead of the expected examples of excellence the practitioners appeared to be poorly educated in this area of practice and found it difficult to discuss with their peers, and the question for me was therefore how on earth do they address the sexuality and sexual health of their patients. Not to mention their clear lack of comfort with and knowledge of LGBT

lifestyles, health and healthcare issues as the lack of eye contact and wriggling on their seats revealed. My comment that I'm really surprised and very disappointed, sums it all up.

My reflections were that I think I need to explore how they have been prepared to meet the needs of their patients in these areas. I therefore need to look at how they have been professionally educated – undertake a documentary analysis. Including the UK government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education (as the study is focussed on the experiences of lesbians and practitioners in the UK. A detailed review of UK. Undergraduate nursing and medical curriculum with regards to the holistic assessment and management of sexuality and sexual health. And an in-depth examination of the U.K. governmental and professional body LGBT specific directives for good patient care practice, together with the LGBT specific content within undergraduate nursing and medical curriculum. This fairly lengthy list was clearly going to impact on the study as a whole. Before proceeding further I needed to record how I addressed the issues arising from this two stage workshop

Reflexive comments:

- Checked potential influence of own past experiences. in regards to workshop format and content with my supervisors prior to ethics application and workshop and questionnaire.
- Scrutiny and justification by /with the ethics committee.
- Revisited existing literature - both sexuality in healthcare in general and cancer specific, to both inform the workshop and questionnaire.
- Very much felt like an 'outsider' not a peer with the workshop participants.

Following this process I then went on to make the adjustments necessary for the study and to research the processes I needed to use to move forward.

Chapter Five: Journey Phase Two (A) - Documentary Review

Documentary Review

Documentary methods refer to the analysis of documents that contain information about the phenomenon to be studied (Mogalakwe, 2006) and are a well-established method within social research (Bryman, 2012, Scott, 2014). However, Bowen (2009) and Scott (2014) remind us that all these documents were not originally written with research in mind, frequently being used in day to day practice and written for a specific professional but not research audience. To gather the data from the various documents a structured format was needed, and therefore data extraction grids were developed. This enabled me to systematically search each document and record the data from the documents.

Positionality for the documentary data review

This additional phase needed to be formally considered with the aims for the review carefully formulated. Care was taken to use the field notes from the workshop and to check that my own biases were not driving the aims I had developed. Whilst making the decision to undertake this additional element within the study I was not fully aware of the volume of work which would be needed. From the outset of locating the nursing and medical school curricula I felt daunted by the number of university faculties involved in medical and nursing education. I had anticipated that through my academic (insider position) I would gain easier access to the documentation needed.

The Aims Of The Review And Analysis Of Documentary Data Sources Were To:

- Documentary review of the UK government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education (up until 2016).
- Documentary review of undergraduate nursing and medical curriculum with regards to the holistic assessment and management of sexuality and sexual health (up until 2016).
- Documentary review of the UK. governmental, professional body and LGBT organisation LGBT specific directives for good patient care practice, together with the LGBT specific content within undergraduate nursing and medical curriculum (up until 2016).

Search strategy

Unlike a traditional literature and research review, in order to locate relevant documents for the review a much narrower focus was taken. Two main search strategies were adopted.

1. Undergraduate nursing and medical curriculum with regards to the holistic assessment and management of sexuality and sexual health and LGBT specific content (Up until 2016):
 - i) Online location of contact details for the relevant 'curriculum manager' for the UK nursing and medical departments/schools.
 - ii) Email contact requesting information of the above content within their programmes (information grid to be completed included). The request for the information requested not the whole curriculum document as this would have had copyright implications.
 - iii) Online location of available curriculum information for the above.
 - iv) Online location of the General Medical Council (GMC) document outlining the core curriculum for undergraduate medical education in the UK.

Sample

Is given below in Table (11)

	Requested	Number of documents reviewed (including online access)
Nursing faculties /schools	75	30
Medical schools	33	10

Table (11): sample undergraduate medical and nursing curriculum content.

2. The UK government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education. Plus UK. governmental, professional body and LGBT organisation LGBT specific directives for good patient care practice (up until 2016):
 - i) Online searching for documents and information pertaining to these areas – UK only.

Data analysis

The information retrieved from the search was collated into tabular format, subjected to content analysis, listing the data separately for each of the areas relevant to the study. As the information sought to clarify the current position and thus was descriptive, no further analysis was necessary.

Assessing the quality of the documentation

Payne & Payne (2004) and Scott (2014) suggested terms and criteria for checking the quality of documents used, including authenticity, credibility, representativeness and meaning.

Authenticity refers to whether a document is genuine and comes from a reliable and respectable source e.g. government department or professional body. Credibility is whether the organisation and nature of the content are similar to other documents from similar sources that is it is typical of its kind. Representativeness refers to whether the documents consulted are representative of other relevant documents, whilst meaning indicates whether the document is clear and comprehensible. As Scott (2014) states the ultimate purpose of examining documents is to arrive at an appreciation of the meaning and significance of what the document contains. Mogalakwe (2006) maintains that government and other official documentation should be accepted as meeting the first three criteria. Although this could be challenged particularly in political environments where corruption is endemic and also where organisations have 'vested interests' in a particular political stance. In this study all the documentation came from official or reputable sources i.e. university curriculum documents, professional organisations, government departments and as they formed the basis for teaching, practice directives and /or political lobbying, their meaning was clear.

Having carefully reviewed the above, the most appropriate way to present the findings from the documentary data is in table format demonstrating data extraction and theme generation, followed by discussion of the main themes and key points which emerged related to the topic area which are presented in sequence below.

Documentary review of the UK government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education (examples from the data extraction grids and theme generation are presented as Tables (12 and 13))

Organisation and document	Subject heading - Sexuality and Sexual Health in Healthcare	Sexuality Education and Training	Sexual Health Education and Training - Recommendations
Department of Health (2013) A Framework for Sexual Health Improvement in England.	Focus on prevention of STI/HIV transmission + contraception. In section Older people aged over 50: Support for people with physical health problems & long term conditions (including cancer) experiencing problems with their sexual health. Cancer survivorship services need to reflect this.	Nil mention.	Arrangements should be in place for continuing professional development, and staff should be supported to undertake appropriate training and development. Professional organisations such as BASHH, FSRH, the British HIV Association (BHIVA) and the Royal College of Nursing (RCN) can advise local areas on providing training for their staff.
RCN (2009) Sexual health competences: an integrated career and competence framework for sexual and reproductive health nursing across the UK.	Focus on prevention of STI/HIV transmission + contraception. Levels of competence. Qualifications per competence level.	Nil mention.	Levels of competence. Qualifications per competence level stated. Nothing re: content of the programmes leading to these qualifications.
RCN (2000) Sexuality & sexual health in nursing practice.	Most people in healthcare settings do not have sexual ill health. But their other health problems or disability may impact on their sexuality. Nurses need to recognise that sexuality and sexual health is an appropriate and legitimate area of nursing activity, and that they have a professional and clinical responsibility to address it. Some nurses not comfortable with dealing with sexuality & sexual health issues. Need to raise awareness of the professional role that nurses can develop in the area of sexuality and sexual health.	Model of practice presented – PLISSIT. Worked examples of addressing sexuality & sexual health in varied nursing settings, including cervical cancer. Use of reflective questions to aid personal & professional awareness.	As per sexuality education & training section.
FSRH Guidance (September 2009) Postnatal Sexual and Reproductive Health.	HCP should create opportunities for women and /or their partners to raise issues relating to postnatal sexual problems, body image and mental well-being, know where to refer if appropriate. HCP should find opportunities during both the antenatal and postnatal period to discuss all methods of contraception.	NIL	NIL

Table (12): extract from the documentary review of the UK government and healthcare professional organisations documents pertaining to the place of sexuality and sexual health within practice and education.

Code	Description of code	Additional comments	Theme
1	STI's.		Biomedical aspects of sexual health – reducing transmission risks and family planning (reducing unintended pregnancy).
2	Contraception.		Biomedical aspects of sexual health – reducing transmission risks and family planning (reducing unintended pregnancy).
3	Impact of ill health on sexual health (including cancer).		Appropriateness of sexuality to health care practice.
4	Legal & ethical aspects of sexual health practice.		Legal and ethical aspects of practice.
5	Many nurses in practice today were trained when sexuality & sexual health were not part of pre-registration education.	RCN 2000 document (the results from current study show that this is situation has now improved). Whilst the focus group c/ o HCP shows that still minimal input & bares out the older trained nurses= no input.	Need for training and education.
6	Nurses embarrassed to address due to: lack of training, lack of relevant experience and own belief system.		Need for training and education.
7	Need for sexual self-awareness when addressing in patient care.		Need for training and education.
8	Signposting to services.		Prevention / sexual health promotion.
9	Post-natal sexual issues.		Appropriateness of sexuality to health care practice.

Table (13): extract from government and professional organisations/ body documents re: sexuality and sexual health UK - data analysis grid and themes.

The documents revealed that as with many health organisations such as WHO (2006), the UK government and professional organisations tend to focus on the prevention of STI's /HIV and the control of fertility (contraception) rather than taking a holistic view of sexual health and sexuality. Overall the documentary evidence showed that whilst there remains an emphasis on the biomedical aspects of sexual health, there are some positive moves

towards taking account of the wider determinants of sexual health. Together with the impact and influence that an individual's sexuality has on their ability to remain 'sexually healthy'.

The apparent focus on the STI /HIV and contraception aspects of sexual health are congruent with the approach and understanding of the educators and practitioners attending the cancer conference workshop and completing the questionnaire. It is hardly surprising that these professionals equate sexual health and sexuality to these narrow, biomedical aspects of care.

Furthermore, despite both the RCN (2000) and DH (2012) documents stating that many long terms conditions, including cancer are known to have detrimental effects on an individual's sexual health, there appears to be minimal guidance given in terms of appropriate education and training in order for the practitioners to address these issues with their patients. The RCN (2000) document goes some way to address this, by providing the useful and well known PLISSIT (Anon, 1970) as a tool to utilise in practice, together with several worked examples from a range of nursing practice fields.

One of the main issues highlighted by the data analysis is that one of the main reasons practitioners identified for not addressing patient needs in this area was their own level of discomfort in dealing with these personal issues. Linked to this is the need to raise awareness of the professional role that healthcare practitioners can develop in the area of sexuality and sexual health. These reflect the findings of studies in this area from the early pioneering work of Woods (1987), Webb & Askham (1987), Poorman (1988) and of the more recent work of Harboubi & Lincoln (2003) and Saunamaki, Andersson & Engstrom, (2010).

Documentary review of undergraduate nursing and medical curriculum with regards to the holistic assessment and management of sexuality and sexual health

Curriculum documents from 30 nursing faculties /schools and 10 medical schools from across the UK, together with the GMC (2015) 'Outcomes for graduates (tomorrow's doctors)' document the core curriculum for undergraduate medical education in the UK were reviewed.

As will be seen from Tables (14) and (15) it is not surprisingly following the lead from government and other health organisation (such as the WHO) both the undergraduate nursing and medical curricula adopted a very biomedical approach to sexuality and sexual health education. Greater emphasis being placed on the biomedical aspects of sexual health such as contraception and prevention of STI transmission. Rather than placing these within the wider context of sexuality and /or the impact on sexual behaviour of the wider determinants of health, such as socio economic upbringing and situation. Additionally, in both nursing and medical education emphasis was given to the ethical and legal aspects of

sexual health, again without placing these within the wider societal context. This was seen to reflect the findings previously presented from the expert panel (see page 54) and offers a partial explanation as to the lack of a more holistic approach to sexuality and sexual health care provided by practitioners. This is seen especially in terms of their preparation to assess and meet the sexuality and psychosexual needs of their patients, even in health care situations where these are known to be effected, such as cancer care. Sadly, reflecting the findings of Zalar (1982) and Thomas (1990) regarding the lack of acknowledgment of sexuality and sexual health within nursing curricula. It is argued here that without appropriate education in these areas, health care practitioners will not feel competent or confident to address the concerns of patients in their care in regards to the impact of their cancer and /or treatments on their sexuality, psychosexual health and relationships.

Code	Description of code	Additional comments	Theme
1	STI's.		Biomedical aspects of sexual health – reducing transmission risks & family planning (reducing unintended pregnancy).
2	Contraception.		Biomedical aspects of sexual health – reducing transmission risks & family planning (reducing unintended pregnancy).
3	Services available c/o STI's & contraception.		Prevention / sexual health promotion.
4	Legal & ethical aspects of practice.	e.g Fraser guidelines, abortion.	Legal & ethical aspects of practice.
5	Sexual health promotion.		Prevention/ sexual health promotion.
6	Anatomy & physiology – reproductive system.		Biomedical aspects of sexual health.
7	Attitudes & taboos.	Mental health nursing only.	Relevance within mental health practice.
8	Psycho – social influences on sexual behaviour.	Linked to STI's & HIV.	Impact on sexual behaviour of socio economic upbringing & situation.
9	Sexual health & mental health.	Impact of SH on different mental health issues (through use of case /practice examples).	Relevance within mental health practice.
10	Sexual health c/o admissions assessment.	Mental health only – how to incorporate a sexual health assessment into admission assessment.	Relevance within mental health practice.
11	Side effects of medication.	Mental health only. Side effects of drugs used in mental health – known to have impact on sexual functioning.	Relevance within mental health practice.
12	Introduction to sexuality.		Appropriateness of sexuality to nursing practice.
13	Impact of ill health on sexuality & sexual health.		Appropriateness of sexuality to nursing practice.
14	Developing sexual self-awareness.		Appropriateness of sexuality to nursing practice.
15	Public health – social determinants of health.		Impact on sexual behaviour of socio economic upbringing & situation.
16	Sexual health c/o child nursing.	STI's, contraception.	Sexual health promotion.

Table (14): Nursing curriculum data analysis grid (theme generation): sexuality and sexual health.

Description of code	Emerging theme	Statement in Original script
Ethics & law.	Ethics & law in clinical practice.	Did I just hear that: Raising & responding to concerns. Legal & ethical issues in medical practice.
Contraception.	Sexual & reproductive medicine.	Essentials of contraception – year 5. Emergency contraception – year 5. Using a request for contraception and symptoms of a UTI explores GU & sexual health histories.
Abortion.	Ethics & law in clinical practice.	Abortion year 2. Clinical aspects of abortion – year 5.
A & P of genitio- urinary & endocrine systems.	A & P.	Urogenital & endocrine systems.
Development, growth & reproduction.	A & P.	It includes anatomical & physiological aspects of reproduction.
Psychological aspects of reproduction.	Sexual & reproductive medicine.	It considers the psychological aspects of reproduction.
Obstetrics & gynaecology.	Sexual & reproductive medicine.	Obstetrics, gynaecology and child health.
Public health.	Public health.	Public health.
Spread of communicable & infectious diseases.	Public health.	Patterns of disease and the spread of communicable diseases. Infectious diseases.
Clinical communication skills.	Sexual & reproductive medicine.	Clinical skills in patient communication.
GU & sexual health history taking.	Sexual & reproductive medicine.	Clinical skills & community sessions for this case will allow you to develop communication skills further to obtain relevant genitio- urinary & sexual health histories in a simulated environment.
Reproductive medicine.	Sexual & reproductive medicine.	Practical knowledge of the speciality in a community setting e.g. cervical cytology, screening for congenital abnormalities, GU medicine, sexual health contraception etc.

Table (15): Sexuality and sexual health – pre – qualifying medicine – data extraction grid and themes.

Documentary review of the UK governmental, professional body and LGBT organisation, LGBT specific directives for good patient care practice

As with the other two elements of the documentary review, key documents from the above were reviewed. The Public Health Outcomes Framework (DH, 2012) and The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document (2013) adopted a more social determinist approach to health. Therefore, the inequalities related to LGBT health were recognised especially the impact on mental health and the effects of internalised homophobia. Further it identified the effects of heteronormative attitudes and behaviours which can lead to failure to address the LGBT specific health needs. Given the purpose of the Public Health Outcomes Framework the document remained focussed on reducing HIV/STI transmission within the gay male community.

With the introduction of equality legislation in 2007 and 2010 the Department of Health (2009) together with LGBT specific organisations such as Stonewall (2010) produced a number of important documents outlining both the requirements of the legalisation and offering practical advice to help healthcare organisations, especially the NHS on providing LGBT sensitive services and care. Extracts from the data extraction grid is shown as Table (16)

Organisation and Document	Guidance
GMC (2005) Sexual orientation in the work place.	Includes: Doctors' responsibilities towards patients. Provision of goods and services. Healthcare needs and promotion. Guidelines for working with lesbian, gay and bisexual patients.
Sexual orientation: A practical guide for the NHS (2009).	A practical advice to NHS organisations to help them comply with equality legislation (2007 & 2010), understand the role of sexual orientation in the context of healthcare.
Stonewall. U.K. (2010) Sexual Orientation A guide with action plans for the NHS.	A practical advice to NHS organisations to help them comply with equality legislation (2007 & 2010), understand the role of sexual orientation in the context of healthcare Including: <ul style="list-style-type: none"> • Training around sexual orientation to all staff who come into contact with patients on how appropriately to treat lesbian, gay and bisexual people. • Train staff to explain to patients why the patient's sexual orientation may be relevant to the care they receive. • Train health practitioners to avoid making assumptions or asking inappropriate questions. • Train staff how to ask open-ended questions, such as "Have you got a partner?" rather than "Are you married?" • Train healthcare staff to acknowledge when a patient tells them they are gay.
The Lesbian, Gay, Bisexual and Trans Public Health Outcomes Framework Companion Document (2013) England.	A series of briefings aims to show that LGBT people can be younger, older, bisexual, lesbians, gay men, trans, from black and minority ethnic communities and disabled, and to dispel assumptions that they form a homogeneous group
Department of Health (2013) A Framework for Sexual Health Improvement in England.	Focus on public health promotion & therefore, it doesn't identify any areas for healthcare practice.
Public health England/RCN (2015) Preventing suicide among lesbian, gay and bisexual young people: A toolkit for nurses.	Includes: Developing a LGB identity. Suicide risk and protective factors. Other factors to consider. Working with LGB young people. Practicalities: how to talk with LGB young people. Motivational interviewing techniques. Effective communication. Sample questions for effective communication. Confidentiality and consent.

Table (16): LGBT specific governmental and professional body directives for good patient care practice: UK.

In addition Public Health England (PHE) and RCN (2015) produced comprehensive training package ‘preventing suicide among lesbian, gay and bisexual young people: A toolkit for nurses’ the contents of which are shown in Figure (8)

Content includes:
<ul style="list-style-type: none"> • Developing a LGB identity • Suicide risk and protective factors • Other factors to consider • Working with LGB young people • Practicalities: how to talk with LGB young people • Motivational interviewing techniques • Effective communication • Sample questions for effective communication • Confidentiality and consent

Figure (8): Preventing suicide among lesbian, gay and bisexual young people: A toolkit for nurses (PHE and RCN, 2015).

These documents offer healthcare staff with clear guidance on the provision of LGBT sensitive care. However, it was clear from the findings from the expert panel (some of whom were from the UK) that staff still feel under prepared to provide this level of care to their patients. Furthermore, as will be seen later this was also true of the practitioners who participated in the focus groups.

The LGBT specific content within undergraduate nursing and medical curriculum (up until 2016)

The curriculum documents from 30 nursing faculties and 10 medical schools from across the U.K. Plus the GMC (2013, 2015) documents ‘Good medical practice’ which underpins all medical practice in the U.K. and ‘Outcomes for graduates (tomorrows doctors)’ document (the core curriculum for undergraduate medical education in the UK) were reviewed. An extract from the data extraction grid for the nursing curriculum is given in Table (17) whilst the key points from the medical school curriculum and GMC documents are presented in Table (18).

Code	Description of code	Additional comments	Theme
1	LGBT within sexuality & sexual health content.		Therapeutic / nurse patient relationship.
2	LGBT within social determinants of health content.		LGBT health within the wider social context (impact of LGBT on health & wellbeing).
3	Impact on health of marginalised groups.		LGBT health within the wider social context (impact of LGBT on health & wellbeing).
4	Relationship between population & health needs.		LGBT health within the wider social context (impact of LGBT on health & wellbeing).
5	End of life care.	Aspects of sexuality in relation to end of life care eg gay partners who have not disclosed and feel they can't attend funerals etc	Therapeutic /nurse patient relationship.
6	Relationships: sexuality & intimacy.		Therapeutic / nurse patient relationship.
7	Gender & sexuality.		Therapeutic /nurse patient relationship.
8	Values based nursing / nurse patient relationship.		Therapeutic /nurse patient relationship.
9	LGBT = HIV.		LGBT = HIV.
10	Mental health & LGBT.	Link between LGBT & mental illness (higher levels of MH issues c/o LGBT community). Links to the PHE /RCN (2015) Preventing suicide among lesbian, gay and bisexual young people : A toolkit for nurses	Link between LGBT & mental illness (higher levels of MH issues c/o LGBT community).

Table (17): Extract from nursing curriculum data analysis grid and themes: LGBT.

Document	Descriptor /content
Outcomes for Graduates (Tomorrow's Doctors) (2015)	Apply theoretical frameworks of psychology to explain the varied responses of individuals, groups and societies to disease.
	Apply to medical practice the principles, method and knowledge of population health and the improvement of health and healthcare - Discuss basic principles of health improvement, including the wider determinants of health, health inequalities, health risks and disease surveillance.
	Assess how health behaviours and outcomes are affected by the diversity of the patient population.
	Take and record a patient's medical history, including family and social history, talking to relatives or other carers where appropriate.
	Respect all patients, colleagues and others regardless of their age, colour, culture, disability, ethnic or national origin, gender, lifestyle, marital or parental status, race, religion or beliefs, sex, sexual orientation, or social or economic status.

Document	Descriptor/content
Good medical practice (2013).	Communicate effectively: You must be considerate to those close to the patient and be sensitive and responsive in giving them information and support.
	Show respect for patients: You must not express your personal beliefs (including political, religious and moral beliefs) to patients in ways that exploit their vulnerability or are likely to cause them distress.
	Treat patients and colleagues fairly and without discrimination: You must not unfairly discriminate against patients or colleagues by allowing your personal views to affect your professional relationships or the treatment you provide or arrange.

Table (18): Extract from LGBT – pre – qualifying medicine – data extraction grid – content.

In terms of undergraduate nursing programmes the review revealed a mixed picture. On the whole the programmes demonstrated more attention being given to the social determinants of health and the impact on health of marginalised groups. Together with the importance of developing a sound therapeutic relationship and the use of good communication skills with all patients and significant others. In addition, the impact of LGBT specifically on mental health and in some programmes on childbearing /midwifery practice.

With reference to the undergraduate medical curriculum, the GMC (2015) 'Outcomes for Graduates (Tomorrows doctors)' identified numerous areas where LGBT health could be addressed and the GMC (2013) 'Good medical practice' identifies expected levels of practice, including LGBT sensitive and appropriate care. However, it is less easy to identify where in the medical curricula these are addressed.

Reflections and Implications for Practice and Education

Throughout the review of the documents it was apparent that there were educational institutions which had tried to embrace both the wider LGBT health picture and the good practice guidelines discussed above. Whilst other institutions demonstrated a lack of these, focussing mainly on the relationship between HIV/STI and the LGBT community. Given this divergence in educational content it is hardly surprising that whilst there are comprehensive guidelines for LGBT sensitive care available, some health care practitioners are not educated to consider this from their pre - qualifying programmes. Unfortunately for the patients in their care the quality of the care they can provide may well be compromised.

In summary, on the whole there appears to be an improving situation possibly reflecting changes in societal attitudes and legislation. There is guidance available to health care practitioners to develop and maintain LGBT sensitive /appropriate care. However, as will be seen from the results of the focus group with cancer specialist nurses in Chapter Eight whilst staff at practitioner level are now more willing to recognise and address sexuality, sexual health and LGBT issues with their patients they are unsure how to do so.

Reflective research journal entry and Reflexive comments:

By this time the reality of the situation I had found could not be ignored and was impacting on my mood and how I felt about the study

"Feeling similar to how I felt post expert panel workshop - have I and others like me made so little difference in terms of curriculum content about sexuality in patient care and LGBT issues and impact on health after all these years. It seems as though undergraduate curricula lag so far behind societal changes and expectations in this area – I wonder in how many other areas this is also the case! I think this may be down to how 'not important' sexuality, sexual health and relationships

Are s to nursing and healthcare in general – I know how difficult /impossible it has been to get these areas (including 'traditional' sexual health) included in the nursing curriculum at my own university - there is always something that is more essential!"

I really needed to write this to make explicit what I was thinking as only that way could I work with the findings and use them appropriately. I also had to accept that I was not singlehandedly responsible for the knowledge and expertise across the country, and that while I could accept that I was disappointed in myself for not sharing my work more widely, I was not to blame for the current situation.

"I experienced problems locating the curriculum documents, this was mainly due (as stated by some of the institution responses) to the institutions concerns re: copyright. My being an 'insider' perhaps exacerbated rather than helped overcome this problem – as universities do not always feel comfortable sharing information with a 'competitor'".

Reflexive comment:

- Discussed and outlined the sources of documentary information prior to undertaking the search and analysis with my supervisors.
- Discussed the documentary analysis with my supervisors to check for any personal bias (especially important as own area of practice).

Up until this stage of the study the views and experiences of lesbian and bisexual women effected by cancer and their partners had not really been heard. The next phase of the journey had to be to seek their views and experiences and give them voice.

Chapter Six: Journey Phase Three (A) – Seeking to hear and listening to the voices of the lesbian and bisexual women and their partners: A phenomenological exploration

Positionality: the challenges of giving the women a voice

As a 50 plus year old lesbian who has had my own particular experience of being a gay woman, who had previously been married to a man, of a particular generation with my own unique experiences of 'coming out' both personally and professionally. I needed to think carefully about how I would carry out interviews and design questions that needed to be asked. I am also a psychosexual and relationship therapist with a particular set of skills and way of working with clients. I needed to be cognisant that these are both powerful influences within my being and ways in which they could consciously or unconsciously interplay with the chosen methodology and analysis of experiences shared by the participants in this part of the study. Through this part of the journey I checked and re-checked that I was listening to what they wanted to say and that my use of data was within their context, not mine.

The Aims Of This Phase Of The Research Study Were:

- To explore the sexuality and sexual health experiences of lesbian and bisexual women who have been diagnosed and received treatment for reproductive and female cancer. Together with the experiences of their partners.
- To explore whether the women experienced any difficulties with their sexual and other relationships as a result of their cancer and its treatment. Where the women are in a couple relationship, to explore whether these impacted upon their experiences of sexual intimacy with their partner.
- To explore their experiences of healthcare practitioners in regards to their sexual orientation and the practitioner's willingness to assess and address any sexuality, sexual health (incorporating psychosexual health) and relationship issues related to their cancer.

Sampling and recruitment strategy

In the case of this phase of the study, homogenous purposive sampling was used as the study required a sample who shared the same or very similar traits, characteristics /experiences i.e. lesbian and bisexual women cancer survivors and partners. Through work undertaken with breast cancer self - help groups it had become apparent that a number of lesbian and bisexual women do experience difficulties with their diagnosis, treatment and the impact upon their relationships. However, currently the available literature regarding female and reproductive cancers gives little or no indication of sexual orientation (Boehmer & Clark et al, 2011), there was nothing to guide the selection of an appropriate sample size. Therefore, the principles of sampling within descriptive phenomenology, which advocates a sample of 10 - 15 (Giorgi, 2009, Englander, 2012) were applied. It was seen as important that the perspective of the partners be included as in this area also there is very limited information. Hence an additional group of potential participants i.e. the partners was included in the sample. It was recognised that the collective sample of **22** women (see Tables 19 and 20 below) is large for a descriptive phenomenological study, but to allow for a range of experiences to be voiced, this was seen as necessary. In reality it was two samples, the women and partners, each with different experiences. From within the sampling framework of a local LGBT Health and Wellbeing Centre and the national LGBT Consortium, together with the later developed website (see page 87) a sample of **16** women meeting the inclusion criteria given below were recruited, in addition **6** partners meeting the inclusion criteria were recruited. The original recruitment strategy was the distribution of a participant advertising leaflet via the groups allied to the LGBT Health and Wellbeing Centre and the LGBT consortium - this was distributed in both paper and electronic formats. The recruitment materials, participant information and consent forms are given in Appendices seven (a) - (d).

Given the sensitive nature of the topic and issues it was decided that individual interviews rather than focus groups would be undertaken. Interviews are a useful method when dealing with sensitive topics, as they offer the women the opportunity to share their experiences and stories, the act of storytelling can be therapeutic and contribute to healing (Leseho & Block, 2005, Newman & Risch et al, 2006, East & Jackson et al 2010). In addition, one of the important elements in phenomenological data collection on sensitive topics is the ability of the researcher to enter the life world of a participant through developing a rapport with each participant (Liamuttong, 2007, Karnieli - Miller & Strier et al, 2009). It is suggested that this is best achieved through individual interviews rather than focus groups. Davis & Bolding et al, 2004 and East & Jackson et al (2010) also suggest that for some participants the disclosure of intimate and personal experiences may feel embarrassing, humiliating or awkward and therefore, they may feel more comfortable with individual interview.

In qualitative research/interpretive research, where purposive sampling is used it is important that those invited to participate meet criteria that will enable the researcher to explore the phenomenon under study. Therefore the following inclusion and exclusion criteria were developed for this phase of the study.

Original inclusion criteria: lesbian and bisexual women and partners

- Lesbian or bisexual women who have had a diagnosis and completed treatment for primary (non - recurrent) breast or female reproductive cancer at least six months prior to participating in the study. Including women taking tamoxifen or aromatase inhibitors.
- Lesbian or bisexual women who are in a current or previous relationship with a partner who has or has had a primary breast or female reproductive cancer.

Original exclusion criteria

This was an initial study and therefore the focus was on women who have had primary breast or female reproductive cancer and completed treatment. Hence the exclusion criteria are as given below.

- Lesbian or bisexual women who have had a diagnosis and treatment for recurrent breast or female reproductive cancer.
- Lesbian or bisexual women who have had a diagnosis and treatment for other types of cancer.
- Lesbian or bisexual women who are in a current or previous relationship with a partner who would be excluded from the study, as per exclusion criteria above.

Data collection

Interviews

The method of analysing phenomena in the phenomenological tradition is reflective (Husserl, 1967, von Eckartsberg, 1986). In phenomenological research initial reflection is by the person who has undergone a particular experience, this reflection is a primary interpretation. It is through thematised verbalisation of this reflective experience that we gain access to the phenomenon experienced, its modes of appearing in natural attitude together with its meaning. Von Esckartsberg (1986) and Bevan (2014) argue that if we accept that vocabulary is shared through culture and a linguistic population, whereby experience is identified and named in a consistent manner, then interviews are a suitable means of illuminating or explicating lifeworld experience. For these reasons phenomenological researchers are drawn towards and tend to

utilise interviews as a method due to their interest in the meaning of the phenomenon as it is lived by the participants (Giorgi, 2009, Van Manen, 2014).

At the root of in depth interviewing is an interest in understanding the experience of other people and the meaning they make of an experience. In addition, for this study, as little information was available from the literature on the topic together with its sensitive nature it was felt that individual interviews would be more appropriate than focus groups, as they allowed for more sensitive and in depth probing questioning. Furthermore, for sensitive topics which people feel uncomfortable discussing an individual interview is regarded as more appropriate than a focus group, as people may feel less self - conscious in a one to one situation (Newman, Risch et al, 2006, Campbell, Adams et al, 2009). However, interviews as a method present both theoretical and practical issues, especially in terms of the appropriate interview strategies to be adopted for a phenomenological study (Bevan, 2014).

This was particularly the case in terms of equality of the power dynamics within the interview situation. It was seen as important that the interview was seen as a shared experience between women who would share knowledge (Oakley, 1981). To that end the interviews were constructed and conducted in a way which allowed for them to be a 'search procedure' - a process of seeking meanings together. As Harding (1991) suggests myself as the researcher shared with the interviewee the concerns which animated the research, so that the conversation unfolded as a collaborative moment of making knowledge (De Vault & Gross, 2006). This involved a degree of appropriate strategic disclosure - sharing of personal information, professional background and research interests (Edwards, 1990). Campbell & Adams et al (2009) argue that the more informed and patient the interviewer is the more helpful the interview can be. They further suggest the need to recognise that there are limits to what the interviewers can truly understand about the sensitive issue (unless they have walked in the shoes themselves) and therefore there is the need for the interviewer to be respectful of the differences between personal and learned knowledge. These are all issues that are components of psychosexual therapy practice and maintained congruence between actions/ ways of being as researcher and therapist throughout the interview processes. Additionally, interviews draw upon skills of active listening, to be fully engaged with the participants. Noting and actively processing both the verbal and non-verbal aspects of the interaction. It was also important to maintain a reflexive awareness throughout the interviews, constantly actively processing the 'I thou' dynamics to ensure clarity of 'ownership' of the issues being discussed by the women. The interview topic guide /schedule is given as appendices seven (e) and seven (f).

After the first few interviews it was apparent that there were real problems with regards to health care professionals practice and therefore the need to change practice came into sharper focus. As an ethical researcher wearing different hats at different times e.g. nurse, therapist and senior educationalist I had to really clearly identify that the study was aimed at changing practice. As identified in Chapter two, whilst planning the study using action research (Reason & Bradbury, 2013, Williamson, Webster & Bellman, 2012) as the underpinning study methodology was considered but rejected it was now clear that throughout the study to date there had been an impetus towards changing practice. Therefore, it was decided that phenomenology would remain the overarching methodology, especially in relation to the data collection and analysis, the study being inspired by phenomenology. Whilst a modified action research approach would be taken to the management of the change in practice from the study.

Difficulties in recruiting participants

Once this phase of the study had begun, difficulties began to arise in locating appropriate participants. These difficulties were seen to reflect the experiences of previous researchers working with 'hard to reach' groups (Penrod & Preston et al. 2003, Ismail & Gerrish et al, 2014). The problems with recruitment were very frustrating for myself as researcher as the extract below from my reflective research journal highlights.

(Reflective research journal entry – researcher).

“So disappointed and angry about the problems I'm having finding women to talk to me and take part in the study. So often I've heard lesbians say that their needs are not looked at and addressed. They feel marginalised and left out – the gay men get all the focus. But then when you ask them for help to make their voices heard they don't come forward & I wonder if they actually want things to improve for them! They should stop moaning if they are not prepared to put their money where their mouth is! Is this another case of 'lesbian apathy??”

After further reflection it became apparent that it would be necessary to utilise additional modalities for recruitment in order to maximise recruitment opportunities. Therefore, ethical approval was sought and gained (incrementally) from the research ethics committee for several strategies to increase potential recruitment:

- Awareness raising activities within the LGBT community which involved attendance at a local Gay Pride, awareness raising workshops with lesbian and bisexual women at a local LGBT health project.
- The use of the LGBT health organisations email and Facebook sites.
- The development of a study website site.

- Advertising in the wider LGBT press and working with cancer specific charities and organisations i.e. MacMillan Cancer Support, Breast Care UK and the LGBT Cancer Alliance.
- Addition of online questionnaires for both the women and partners.
- Widen the inclusion criteria to include all primary cancers.
(See Appendices two – four for ethics approval letters)

Widening the recruitment criteria

With the decision made and approval gained to extend the recruitment to include women with **all** types of primary cancer it was necessary to amend the overall study aims, together with the inclusion and exclusion criteria for recruiting the participants, outlined below.

The Revised Study Aims:

- To explore the sexuality and sexual health (incorporating psychosexual health) and relationships experiences of lesbian and bisexual women who have been diagnosed and received treatment for cancer.
- To develop a conceptual framework for practitioners working with lesbian and bisexual women in the fields of cancer care in regards to their sexuality, sexual health (incorporating psychosexual health) and relationships.
- To make recommendations for policy, practice and professional education to enhance the quality of care and hence quality of life of this marginalised group.

Revised inclusion criteria: lesbian and bisexual women and partners

- Lesbian or bisexual women who have had a diagnosis and completed treatment for primary non - recurrent cancer at least six months prior to participating in the study. Including women taking tamoxifen or aromatase inhibitors.
- Lesbian or bisexual women who are in a current or previous relationship with a partner who has or has had a primary cancer.

Revised exclusion criteria

This was an initial study and therefore the focus was on women who have had primary cancer and completed treatment. Hence the exclusion criteria are as given below.

- Lesbian or bisexual women who have had a diagnosis and treatment for recurrent cancer.
- Lesbian or bisexual women who are in a current or previous relationship with a partner who would be excluded from the study, as per exclusion criteria above.

As a result of expanding study aim one, revising the inclusion and exclusion criteria for participants extending the recruitment to include lesbian and bisexual women with all types of primary cancer, it was necessary to return to the literature to review the information regarding the impact on sexuality, sexual health (incorporating psychosexual health) of some of the other types of cancer. Following breast cancer, lung cancer and colorectal cancer are the two most common forms of cancer experienced by women in the UK with 11.8 percent and 10.4 percent of new diagnosis respectively (Bate & Baker, 2015). A brief review of the available literature for these two cancers in relation to the subject area of this study was therefore undertaken.

Colorectal cancer – side effects of treatment

It is known from a variety of studies that colorectal cancer and treatments can negatively impact upon a women's sexuality and intimate relationships (de Silva, Hull & Roberts, 2008, Beck & Justham, 2009, McIntosh, Pardoe & Brown, 2013). The treatment modalities used to treat cancer including surgery, radiotherapy and chemotherapy all have a direct and indirect impact physiologically on the women's sexual function and sexuality. Following surgery, due to parasympathetic nerve damage the women may experience lack of sexual arousal and reduced vaginal lubrication leading to dyspareunia and secondary vaginismus. In addition they may also have a shortened vagina which further contributes to dyspareunia, they may experience loss of sexual desire and reduced orgasmic capacity (de Silva, Hull & Roberts, 2008, White, 2013). The neo-adjuvant radiotherapy used to treat colorectal cancer has also been shown to cause fibrosis, adhesions and vaginal shortening, together radiation to the ovaries causing permanent menopause for some women (McIntosh, Pardoe & Brown (2013, O'Gorman, Denieffe & Gooney (2013). Whilst Brunheim, Tveit & Skovlund (2010) also found that women treated with both surgery and radiotherapy experienced significantly more sexual problems than those treated with surgery alone. In addition to the physical effects the women also experience an altered body /self-image, low self - esteem, feel less attractive and fear leakage from their stoma bags or faecal incontinence. All of which lead to a reduced desire for sexual contact (Beck & Justham, 2009, McIntosh, Pardoe & Brown, 2013).

On the whole the main problem with the research studies undertaken with women with colorectal cancer is the very low response rates to the questionnaires used, leading to small

sample sizes and thus causing difficulties in generalising the results. An exception to this problem of small scale studies was Notter & Chalmers (2012), who obtained information from 203 women via a postal questionnaire. Although the results focussed on other quality of life issues for people living with a stoma, the study did identify that 37 percent of the women in their study experienced difficulties with their body image. Another issue encountered when trying to compare the findings from the above studies was the lack consistency in using validated questionnaires. However, overall the majority of studies found that colorectal cancer and treatments negatively affected women's sexuality and intimate relationships. This reinforced the perception that a diagnosis and treatment regimens of /for all types of cancers can impact on the physical expression of a woman's sexuality.

Lung cancer – side effects of treatment

Despite being a commonly experienced cancer there appears to be very little research literature related to the impact of lung cancer on individual's sexuality, sexual health and relationships. Only two recent research-based articles were identified (Schwartz, Plawecki & Henry, 2002, Lindau & Surawska et al 2010), and it was not possible to locate any studies which looked specifically at the effects on women. The issues identified in the studies reflected those from those previously discussed in regards to the impact of chemotherapy and radiotherapy. In addition, one problem which was more specific was the effect of shortness of breath on sexual functioning (Schwartz, Plawecki & Henry, 2002). Lindau & Surawska et al (2010) who in their study interviewed 13 married couples found that the cancer had both negative and positive effects on the couple's relationships. The negative effects being the result of the negative physical and psychological effects of the cancer and treatments. Whilst the positive impact included an increase in non-coital intimacy and a greater appreciation of the spouse (possibly driven by the fear of loss). Clearly the impact of lung cancer on individuals and couples sexuality, sexual health and relationships is also urgently needed in order for practitioners to an evidence base available to guide their practice.

Website development and online questionnaire

Some of the difficulties with the recruitment of appropriate participants were seen to be due to the sensitive and personal nature of the subject areas. In addition, when discussing the issues of recruitment with members of the LGBT cancer alliance it was suggested that the women might find it too difficult to talk about their cancer experiences in relation to their sexuality and sexual health with myself as an 'unknown' to them, researcher. It was therefore suggested that, as with other recent project work undertaken by the group, that the use of online questionnaires addressing the same questions and topics as the face to face interviews would potentially 'unlock' the door for participants.

To this end a study website was developed containing awareness raising and study specific information, including participant information literature. The website also contained a link to the specifically designed online questionnaires which reflected the interview schedules - one for the lesbian and bisexual women and another for the partners, hosted by the Bristol online questionnaire platform. In this regards it was possible for the information shared by the participants to remain confidential to themselves and myself as researcher. In addition, by completing the questionnaire the participants were providing consent for their participation in the study. A critique and rationale for use of questionnaires per se is given on page 59 – 60.

Hearing And Listening to the Voices Of The participants: The Interviews and Online Questionnaires.

The details of the nature of the cancer, treatments and relationship ‘history’ of the women who participated in the survivor and partner interviews and questionnaires are given in Tables (19) and (20) below. It was apparent from the interviews and questionnaires that the participants were all lesbians, with no bisexual women participating. This has clear implications for the recommendations from the study.

Type of cancer	Number of women (Total = 16)	
Breast.	10	
Bladder.	1	
Epithelioid haemangioendothelioma.	1	
Bowel.	2	
Uterine.	1	
Lymphoma.	1	
Type of treatment	Number of women	
Surgery.	12	
Radiotherapy.	6	
Chemotherapy.	8	
Still taking treatment.	Yes = 9 (Tamoxifen)	No = 7
How long ago finished treatment.	13 months - 2 years = 2 Longer than 2 years = 14	
In a relationship at time of cancer and treatments.	Yes = 13	No = 3
How long in the relationship at time of diagnosis and treatment.	Less than 6 months = 1 6 months - 12 months = 0 13 months - 2 years = 3 Between 2 years - 10 years = 3 Longer than 10 years = 6	

Table (19): Details of survivor interview and questionnaire participants.

Type of cancer	Number of women (Total = 6)
Breast.	2
Cervical.	2
Bowel.	1

Multiple myeloma.	1	
Type of treatment	Number of women	
Surgery.	5	
Radiotherapy.	4	
Chemotherapy.	3	
Still taking treatment.	Yes = 3 (Tamoxifen)	No = 3
How long ago finished treatment.	13 months – 2 years = 1 Longer than 2 years = 5	
How long in the relationship at time of diagnosis and treatment.	Less than 6 months = 0 6 months - 12 months = 0 13 months - 2 years = 1 Between 2 years - 10 years = 2 Longer than 10 years = 3	

Table (20): Details of partner interview and questionnaire participants.

Data analysis /explication: Interviews and online questionnaires

To be true to the descriptive phenomenological project and methodology (Husserl 1931, Giorgi, 2009) required that I made sense of the data and synthesised it in such a way that the data, in this case the women's voices were adequately represented and the phenomenon was 'opened up' within context for those reading this work. The focus was on seeking for explicit and hidden meanings through the iterative examination of the data (Finlay, 2011). This process involved myself dwelling with the data, examining it and then progressively deepening understanding of the meanings that 'came to light'. As a novice researcher I searched for an appropriate model to guide me through this process. Having explored several, namely Hycner (1999), Groenwald (2004) and Wertz & Charmaz et al (2011), I decided to be guided by Giorgi's (1985, 1997, 2009) stages to undertaking the analysis, as these stages appeared to be most in keeping with Husserl's (1931) original phenomenological approach - allowing the articulation of the given as given, through the use of the epoche', intentional analysis and eidetic reduction to bring the pre - reflective lived world of the women to light.

The aim of phenomenological reduction (epoche') is to reachieve contact with the world by suspending pre judgements, **bracketing** assumptions, deconstructing claims and restoring openness in order to reach beyond the natural attitude of taken for granted meanings and understandings (Finlay, 2010, Van Manen, 2014, 2015). Through this to see the world as we experience it rather than how we think about or conceptualize it. The taken for granted assumptions, opinions and theories are temporarily suspended (or at least acknowledged and kept in abeyance) in order to see the world in a new way (Finley, 2010). In order to understand the unique meaning and significance of something we need to reflect on it with thoughtful attention. By the use of **free imaginative variation** the researcher 'searches for' the essences

of the phenomenon being explored, that is the most invariant meaning for. Through this **eidetic reduction**, patterns of meaning or themes begin to emerge. This process of Intentional analysis is always constitutive analysis: an explication of how meanings of things are constituted in and presented by consciousness or cognition. All of these are both essential components of the phenomenological attitude and phenomenological reduction.

In addition, throughout the analysis the approach advocated by Giorgi (1985, 1997, 2009) was supplemented by processes advocated by Finlay (2009, 2011) to facilitate deeper reflection, reflexivity and understanding were utilised all of which are outlined below.

The reading of the data – gaining a sense of the whole

The beginning of this stage and to allow me to dwell ‘with’ the data I chose to undertake the verbatim transcription of the interviews, observational interview notes and reflective log myself, rather than outsourcing these to a more experienced transcriber. I also viewed undertaking the transcription as being more ethically sound given such sensitive material. Whilst very time consuming this allowed me to ‘live’ with the data throughout the research journey, hence respecting and honouring the women’s own personal cancer journeys. Furthermore, it allowed me to relive the experience of the interviews reminding me of the nuances, silences, non-verbal and paralinguistic aspects of the interviews, which Finlay (2011) reminds us are so important when ‘grappling’ with implicit meanings. In addition, I immersed myself in the online questionnaire ‘voices’ of the women by reading, re - reading and returning to the questionnaires.

Giorgi (1985) and Bentz and Shapiro (1998) caution that the researcher must allow the findings to emerge from the data without allowing their own intentionality to shape what emerges. Giorgi (1987) further suggests that phenomenology is holistic and therefore it is essential for the researcher to gain a grasp of the whole, rather than disconnecting the given experience from the context in which it is based. Therefore, in order to identify the essence of the meanings in relation to women’s perceptions, I carefully read the transcripts and questionnaires numerous times, rigorously scrutinising every word, phrase, sentence and paragraph in order to gain a global sense of the data.

Dividing the data into parts – discrimination of meaning units

Having gained a global sense of the data, whilst still maintaining a phenomenological stance, the next stage was to explore the transcripts and questionnaires to establish what Giorgi (1997, 2009) terms **meaning units**, to make the data more manageable. I marked every point in the text where there was a transition of meaning, moving from one topic to another. Furthermore, this involved re reading the transcripts and questionnaires through the ‘lens’ or

attitude of an appropriate discipline – in this case, as the study was seeking to explore the lived experience of the women in terms of the effects of cancer on their sexuality and sexual health - that of psychosexual and relationship therapy. I then applied both phenomenological reduction, searching for all possible meanings in the specific text. And as identified when discussing my positionality, modified bracketing ensured that I was able to set aside my own assumptions, experiences and professional theoretical models to identify the essential themes or essences of the phenomenon. During this stage I also adopted the questioning approach advocated by Finlay (2011) to further integrate the data and enter deeper into the world of the women. To this end I used lifeworld orientated questions suggested such as, for self - identity ‘what does it mean to be this person?’ Mood as atmosphere – ‘Is there a tone /mood attached to the phenomenon? What background existential feelings are being express e.g. fretful or yearning?’ Embodiment – ‘What is her subjective sense of embodiment?’ (Interviews only) and relationships - ‘how does she experience relating to others?’

Organisation and expression of the data into disciplinary language. Together with expressing the structure of the phenomenon

Next, within each interview transcript and questionnaire every meaning unit was examined, probed and re described in discipline specific /appropriate language to clarify the experience or feeling being described making the disciplinary value of the meaning units more explicit. Giorgi (1997) argues that this is transformation of the participant’s everyday language into that which is discipline appropriate, brings the often implicit and hidden experiences of the participant’s life - world into the everyday parlance of the professionals within and related to the discipline. Giorgi (2009) further argues that we cannot use the participants words alone as these are given from the perspective of everyday life (life-world) and that from a phenomenological perspective, life-world is pre-theoretical and pre - scientific. Hence, if the experiences of the participants are to be given credence by the ‘scientific community’ and professionals requires that these are transformed into discipline appropriate language.

In order to achieve the transformation of the life-world language of the participants into that which was discipline appropriate, I considered each experience from different aspects by the use of **free imaginative variation**. This is described by Giorgi as “changing aspects or parts of a phenomenon or object, to see if the phenomenon remains identifiable with the part changed or not” (Giorgi, 1997 p243,). By utilising the method of Husserlian eidetic abstraction /reduction I explored multiple possibilities and was able to become aware of those features and components which could not be removed, and were thus essential for the object to be given to consciousness, representing the essence of the phenomenon.

Once this had been achieved, I then revisited all of the transcripts and questionnaires to produce ‘typical’ structures, essences and their relationships in order to produce an explicit formulation of generality. In addition I rechecked the identification of any variations by returning to the transcripts and questionnaires, and rendering intelligible /identifying the clusters of variation. Throughout the processes identified above I utilised the data provided by my field notes and reflexive diary, which included a summary of the distinguishing interview and questionnaire features. Together with my reflections on the interviews this included my direct observations of the body language, posture and paralinguistic elements not only during the interview, those that occurred in the relationship between myself and the participants prior to and following the interviews. The field notes also included my analytical memos or end of the ‘field day’ summary. Keeping the reflective diary was an essential tool to facilitate my own continued modified bracketing use throughout the interview and on reviewing of the online questionnaires processes in a self-aware and meaningful manner. Data derived from these were utilised as part of the contextual checks used to add to the methodological rigour of the study (Koch, 1994, 2006, Lofland & Lofland, 1999, Wall & Glenn et al, 2004).

Findings: The Women’s Voices Being Heard And Presented – The Survivors

An integrated presentation within phenomenology is about finding the essences which are context specific. Therefore, the interview transcripts and online responses were supported by the reflective notes and research journal to give contextual meaning to the analysis. Tables (21) and (22) offer extracts from the analysis and reduction.

Table 21: Extract of initial unit coding – Interviews and online responses.

Code and code descriptor	Original transcript	Reflective initial comments
17 Support group heterosexual.	P1 p10	Stereotyping of female sexuality and sexual identity. Doesn’t meet the needs of all sections of the community.
18 Hidden sexuality and fear re: coming out within support group.	P2 p4,5,6	Hidden identity of a group.
19 Coming out in the support group.	P2,p7	Fear of homophobia from group members & organisers.
20 Support group geared up for a certain type of women/ femininity.	P2,p5	
21 Internalised homophobia, wanting to fit into support group.	P2,p6, P2 p11	The felt need to go back into the closet.

34. Facilitation the support group to 'give permission' to people from different sexual orientations and lifestyles.	P2,p7 & p11	Need for group leaders /facilitators to consider making the groups a safe place for minority women. Women feel attending groups at very vulnerable time, don't need to have to consider whether it is safe to be open /out in the group. Self-monitoring disclosure at time of vulnerability.
36. Support group not a 'safe place' to come out /be open re: LGBT.	P2,p8 & 11	The felt need to go back into the closet.
22. Fear of being sexual, entering into a relationship.	P2,p7,p13	Too scary to start a new relationship – fears of rejection etc, at time of vulnerability.
46. Doesn't feel attractive.	P2 p13	Previous abuse /rape history – impact of this on current situation. i.e. antecedent The impact of body image on wishing to be sexual with another person.
41. Impact on self-image.	P2p10	The impact of body image on wishing to be sexual with another person.
67. Effected relationship.	P8, P10	Alterations in relationship roles and dynamics.

Table (22): Extract of searching for connections across emergent themes – Interviews and online responses.

Code descriptor	Original transcript	Reflective initial comments	Emergent theme
Support group geared up for a certain type of women / femininity.	P2. And that is exactly, it's incredibly heterosexual it's for, yeah know it's all very feminised, it's all about make-up, it's all about particular type of what you wear and whatever. P2. It's just this, there an issue about what it meant to be a woman in this. There is only one type of woman, of woman and the other bit is that I tried the big support that they think they are offering is through the xxx breast cancer group. And that is exactly, it's incredibly heterosexual it's for, yeah know it's all very feminised, it's all about make-up, and it's all about particular type of what you wear and whatever.	Stereotyping of female sexuality and sexual identity. Doesn't meet the needs of all sections of the community.	Support group facilitators /organisers failing to recognise the needs of diverse groups of women.
Facilitation of support groups to 'give permission' to people of different orientations.	P2 but that not enough and you need to say that families come and relationships come, you need as the leader of the group to set this differently , you need to say that relationships come in all sorts and you know and need you to state it at the beginning because that gives more permission. P2 Um, I would love to meet some, yeah, I think that s odd isn't it I think there's specifics of in those little groups, the psychologist & the nurse they need to do something, to do some welcoming at the beginning that it's not hard to do that that just sets that & just gives that permission. It's the same as like just a few little symbols it can be just done. That needs to happen more.	Need for group leaders/ facilitators to consider making the groups a safe place for minority women. Women feel attending groups at very vulnerable time, don't ned to have to consider whether it is safe to be open /out in the group. Self-monitoring disclosure at time of vulnerability.	Support group facilitators / organisers failing to recognise the needs of diverse groups of women.
Fear of being sexual, entering into a relationship.	P2 (silence) I can't afford to be hurt. It's like I'm surviving, I'm doing alright I can't risk another, argh, something going wrong 1. um 2. It feels like I've just about clambered up, there isn't enough um, resilience there to take that risk. P2 We just, we have been on holiday together & we have said no we not doing that, not going anywhere, and that's fine. And that's feels a relief , but actually I feel there's a bit I haven't explored, there's a bit isn't, I've put a safety on it to make that do.	Too scary to start a new relationship – fears of rejection etc, at time of vulnerability.	Impact/effect on sexuality and relationships.
Impact on body/ self-image.	P2 so what are you looking at. But actually it, that matters how I feel about myself. Which then impacts on well how do I feel about ever being physical with somebody, I feel really quite strange about all of that stuff.	The impact of body image on wishing to sexual with another person.	Impact /effect on sexuality and relationships.
Doesn't feel attractive.	P2 Yeah, yeah I don't feel attractive (laughs), did I ever- I don't know so um.	Previous abuse/rape history – impact of this on current situation. i.e. antecedent	Impact /effect on sexuality and relationships.
Effectuated relationship.	P8 during my illness my partner took on most of the household type tasks – we had lots of help from our friends – who were great (we couldn't have done it without them especially as my partner was working full time). It was hard for me, because I wanted things and how we were together to be the same, but it wasn't possible. P10 when I was having my treatment we carried on as much as normal as possible. But that wasn't easy, so my partner ended up doing most of the household jobs etc. I was still able to do the joint finances bits. A lot of the time during treatment I felt really quite ill, so my partner took on the 'carers' role more - which caused her a lot of extra work - which was difficult as she was still trying to work full time. She didn't say much, but I could tell from her non-verbal's that she was tired and at times pissed off (not with me, but at the situation)." (Questionnaire participant 10).	Alterations in relationship roles and dynamics.	Impact /effect on the women's relationships.

Having undertaken the analysis above the interviews and questionnaires produced a wealth of rich information. Within phenomenology it is important not to prioritise some 'findings' over others, following the process of phenomenological explication it was not possible to reduce the number of themes further without losing the essential essence of what the women had shared. As a result six main themes were generated, these are identified in Table (23) this is followed by individual exploration of each theme.

Impact /effect on the women's sexuality and sexual health.
Sexuality and sexual intimacy not important during treatment phase but is important in the survivorship period.
Impact /effect on the women's relationships.
The rollercoaster ride of cancer.
Fear of homophobia: relationships and interactions with healthcare professionals including sexuality not discussed by healthcare professionals.
Support groups and helplines stereotypically heterosexually focussed.

Table 23: Interviews and online responses themes

Impact /effect on the women's sexuality and sexual health

The impact of their cancer and treatments on the women's sexuality was identified by most of the women as negative. It appeared to be multi-faceted, affecting numerous different areas of the women's sexuality and sexual health (including psychosexual health) resulting in them being severely challenged by their cancer experiences. The majority of the women had experienced and were experiencing an **altered body image**, which was either confined to their treatment period mainly as a result of chemotherapy (particularly hair loss) or was a long term alteration due to surgery (especially scars, mastectomy or stoma formation). This altered body image had directly affected the women's sense of attractiveness and femininity.

"Felt like a medical 'machine' or 'monster' - all the surgery, scars and then the chemo and I lost my hair (all over - I wasn't expecting that). I really felt unattractive and couldn't see how she would find me attractive. We are both very much into how we look - always wanting to look good, quite feminine and not butch at all. The hair loss was really devastating to me - it really said to the world 'here is someone with cancer', there was no hiding it. I had reconstruction because I felt I wanted to be a whole woman. My partner said she wasn't bothered either way - she would love me whatever, but I wasn't convinced she really meant it. My breasts were always a good part of our intimacy/sex together so I couldn't imagine not having one breast."

(Questionnaire participant 10)

"I felt pretty bad about myself - hair and toe nails falling out, exhaustion etc. My confidence was shattered I had always liked my body but now felt ugly and unattractive and afraid."

(Questionnaire participant 3)

The women also highlighted the central importance to them of how their partners viewed and responded to their changed body image. Those women who were able to talk with their partners about the changes and gain reassurance about their partner's unaltered feelings towards them appeared to adjust to their altered body image better than those women where this was not the case. Interestingly, some of the women were surprised at how important their body image and others view of any changes in this had become to them, as they had previously believed that this was not so important to them as lesbians as it was to their heterosexual counterparts. This clearly effected the way in which they viewed themselves sexually.

"and the odd thing is, is that I'm surprised at that , I'm surprised because I've always thought and my experience of being a lesbian and attraction is that actually it would matter less"
(Interview participant 2)

Many of the women said that they **did not feel attractive** and **felt 'dirty'** and could not see or understand how their partners could find them attractive and want to be sexually intimate with them. This was particularly the case for those women who had stoma surgery for bowel cancer. Some of these women had been able to resolve these issues with their partners, whilst others had not.

"After the operation I was, felt really disgusted by the stoma and the bag – it felt like being a child again but worse as I had even less control of what and when the poo came out. I felt dirty - couldn't see how my partner would want to touch me again or even be in the same room. We did talk about this and lots of other things and were able to work through it together."

(Questionnaire participant 8)

"We tried to stay physically close but the bag got in the way - I didn't like being close in case it leaked and was really aware that it might smell. My partner was really lovely and kept trying to reassure me that it was all OK, but I just couldn't 'go for it'."

We tried talking about it - we have always been able to talk well together and usually manage to overcome any problems this way. This time this hasn't seemed to work."

(Questionnaire participant 9)

Linked to both the feelings of altered body image and attractiveness was the issue identified by several of the women in regards to **loss of their self and sexual identity**. This impacted on their self-confidence and willingness in engaging in any intimate contact with partners or potential partners. A number of the women had previously seen themselves as 'strong Amazonian women' and were shocked by their own perceived weaknesses. Additionally, it altered the way they viewed their place in the world. In some instances this alteration in the way they saw the world was transient and although their lives did not return, unaltered to their pre cancer lives, they were in time able to adapt to their 'new reality'. The question has to be

asked as to how this 'new reality' effected their lives in general and the relationship dynamics within their intimate and other life relationships.

" .. That's quite odd, so at the moment it feels, that the cancers done something to my sexuality, sexual identity it's interesting... You see I can't see at the moment I can't imagine having a sexual relationship that's interesting, odd thing, um."
(Interview participant 2)

"I kind of identified a lot with older people I saw on the street And round the corner from us is a community centre particularly for older people and I went there I went to an art class there and a French class there and go to the café there I was kind of sort of at times I was taking on that identity, Um, and I couldn't do my old things that used to do swimming, cycling gardening and um. Also at the depths of the worst times I couldn't string my thoughts together couldn't concentrate couldn't read a book could barely read the paper. Could barely construct a shopping list you But now I'm back to writing going to this creative writing class writing the article reading novels."
(Interview participant 3)

Other women talked about the impact of the menopause, precipitated by their treatment with Tamoxifen) has had on their sex lives. This was mainly due to problems with vaginal dryness, reduced lubrication and vaginal atrophy, leading to dyspareunia at times. In addition, several of the women also experienced alterations in sensation and sexual feelings due to either the side effects of chemotherapy or the direct impact of surgery (including breast reconstruction). This had led to some women having difficulty in becoming sexually aroused when they returned to being sexual with their partners. Many of the 'usual' erogenous areas had ceased to be sensitive and the women had had to learn new ways and places to touch sexually.

"We had to learn how to touch in different places (the old places weren't always so sensitive anymore – especially my clitoris - so more stimulation was needed and we even found our old vibrator out and found that really useful (I had forgotten the fun we had had with this before!)"
(Questionnaire participant 11)

The direct impact was expressed by one of the women (who had surgery for bladder cancer) in the following way, which highlights the strength of the distress this was continuing to cause her, something which she stated elsewhere was overlooked by her healthcare team.

"My operation removed part of my vaginal wall and there was a real possibility of damage to clitoral sensitivity. When you talk about sex problems after bladder removal, everyone assumes you mean penetrative sex (which may or may not be possible afterwards). The loss of feeling to the clitoris is not considered important – it was WAY more important to me than penetration (and I'd imagine lots of other women!)"
(Questionnaire participant 5)

A number of the women expressed that they were fearful of getting involved in a sexual relationship for several reasons. Firstly, there was the uncertainty they felt around when to

disclose their cancer history to a potential new partner. Clearly this involved the fear of rejection, a fear that most people have when setting out on the potentially exciting venture of a new relationship. For the women in this study this fear was exacerbated by both the vulnerability they already felt stemming from their cancer and the impact of treatment and the worry about how people view the 'death sentence' of cancer.

(silence) "I can't afford to be hurt. It's like I'm surviving I'm doing alright I can't risk another argh something going wrong it feels like I've just about clambered up there isn't enough um, resilience there to take that risk."

(Interview participant 2)

"Initially she was a bit concerned about getting involved because of my prognosis, she was worried that she would be left heartbroken /wouldn't cope, if I died."

(Questionnaire participant 4)

"..I find it difficult to talk about or even tell them (potential new partners) I had cancer because I think they won't want to get into a relationship with me in case I get ill again."

(Questionnaire participant 6)

Sexuality and sexual intimacy not important during treatment phase, but it is important in the survivorship period

Almost unanimously the women said that at the time of diagnosis and throughout the treatment of their cancer sexuality, including sexual orientation and sexual intimacy were the last thing on their agendas. The overriding priority for the women and their partners at this time was survival, anything else was secondary. In some cases, the needs or concerns of their partners were also too much for the women to consider. At the time of diagnosis many of the women expressed their shock and disbelief, this was quickly followed by the all-consuming treatment regimens with what felt like endless rounds of hospital appointments, treatment and scans/tests. This became their 'new reality' with all of its attendant difficulties and fears.

"... you know our relationship or sexuality and all that was not the thing upper most in our minds it was the worry about this bloody cancer..."

(Interview participant 3)

"During treatment all real sex was off the agenda - neither me or my girlfriend felt like it. We were both just getting on with me getting better."

(Questionnaire participant 11)

The women told of how they had no interest in being sexual or intimate with their partners as they felt too tired, nauseous /sick, in pain and stressed to be concerned or engage in intimacy with their partners. The side effects of many of the treatments used in cancer management cause unwanted and difficult side effects (as outlined in Chapter Three). Whilst patients are made aware of these side effects and a wealth of supporting information giving literature is available to them, most people either undergoing or caring those for undergoing these

treatments do not really have a full understanding of the reality until the treatment regimens commence. Furthermore, people often underestimate the levels of fatigue that the treatments cause, and the possible impact this can have on the lives. It is hardly surprising given both the enormity and life altering impact of the diagnosis, together with the effects of treatment that the women did not feel able to be intimate with their partners.

“Didn’t feel like having sex for a long time, with the chemo mainly. Felt sick and tired really tired. Didn’t feel sexy anymore because of the state the operation left - I had lumpectomy but the scar was bad and my breast looked odd.”

(Questionnaire participant 7)

“When they told me I had breast cancer the sexual side of our relationship took the back burner During the chemo I felt crap sick tired and washed out All I could think about was getting through the drug cycles and for it all to be over.”

(Interview participant 4)

In addition, several of the women spoke about pushing their partners away if they believed that their partner was wanting to be intimate with them. It is not uncommon for people to misinterpret their partner’s behaviour, often projecting onto them their own anxieties. As will be seen later when discussing the partners experiences this misinterpretation led some of the partners to feel rejected and hurt, as sexual intimacy was the last thing on their minds whilst the person they loved was experiencing such a dreadful time. It is well known within psychosexual and relationship literature (especially from an objects relation perspective) that people often find it difficult to express their intimate and loving feelings towards a partner in any other way than through being fully sexual with them (Daines & Perrott, 2000). It was, therefore not surprising that both the women and their partners experienced difficulties in this area through their cancer experiences, as the patient would feel ‘pressured’ by their partner whilst the partner would feel hurt and vulnerable when they were ‘rejected’ by their partner.

“For a while we stopped having any intimate (sexual contact) - whilst all the treatment was happening - I really didn’t feel I had the energy or the desire to. I was too busy with trying to get better, to get through the dreadful treatment (I was sore from the operation and felt so sick with the chemo. I just couldn’t have cared less about making love with my partner - I would freeze if I even thought she was wanting to be intimate. I pushed her away a lot - we were normally tactile (even if we didn’t have sex), but I just didn’t want to be touched at all. I guess it was hurtful for her, but I didn’t care really (I felt so awful)”

(Questionnaire participant 10)

However, some of the women felt that a wedge had been driven between them and their partner, with no physical none ‘instrumental’ contact with their partners, such as any hugging or holding being given. These women missed the closeness that these would normally bring, leaving them feeling ‘all at sea’ about their feelings towards their partner and lonely within the

relationship. It is sad to see this dynamic being played out between couples at a time when both are feeling scared, vulnerable and in need of loving.

"I would have liked some intimacy but not the usual full on sex. My partner did not seem as interested in any intimacy and this really hurt."
(Questionnaire participant 3)

So, whilst sexual intimacy was very much 'off the agenda' for the women during their treatment phase for most it was something which they and their partners found to be more important again once the treatment /s had finished. For these women the sexual side of their relationship was something which returned gradually, as they began to feel stronger and more 'normal' again. As would be expected the resumption of sexual contact was something which took time and was taken slowly, often with a degree of hesitancy, allowing both of the women in the relationship to re find their role within the relationship. Moving back away from the 'cared for' and 'carer' dynamic back to a more adult, equal relationship.

"... and then it sort of gradually came back after. A big step actually.....I think there was some hesitations and taking it slowly really ...just being close being intimate you know not always going for orgasms and stuff."
(Interview participant 3)

A number of the women experienced huge alteration in their sexual relationship with their partners in several ways. Some found that they had to 'renegotiate' the nature of the sexual relationship finding that they needed to be in control of any sexual intimacy with their partners. It appeared that most of these women were struggling with a reduction or loss of sexual desire possibly as a result from their continued treatment with Tamoxifen, whilst for others it was in relation to their altered body image and changed feelings of 'self'. In addition, some women said that they had never been able to resume their pre cancer sexual or intimate relationship with their partners, leaving them feeling angry and frustrated. Fortunately most of these women reported that their relationships were strong enough to adapt to these changes.

"We didn't really try to overcome the problems we were having - my loss of desire and willingness to be touchy, feely. Eventually once the treatment finished and I started to get more energy back we started to get back our more intimate times - but always on my terms - I don't know how she felt about this, but she seemed ok to take everything at my pace."
(Questionnaire participant 10)
"I had no sexual feelings....although we had always been able to talk about things and overcome any problem, this time it hasn't seemed to work and I think we are both now used to no physical contact, that we just don't bother."
(Questionnaire participant 9)

As stated previously some women found they couldn't tolerate any closeness and intimacy with their partners during their treatment. However, those women for whom this intimacy had

been possible found that it not only added to the closeness of their relationship during their treatment but it also proved to be beneficial when becoming more sexual with their partners in the post treatment or survivorship phase.

“We have always been very tactile with each other and this has continued to be the case through my cancer experience - we still touched and hugged a lot. Indeed we probable did more hugging and holding than before - we both needed the comfort we could give each other. The times when things were tough were different for both of us, so we needed different things from each other at different times. When my treatment all finished and things started to get back to some sense of normal (although this was a different normal than before) we got back together - slowly at first, just gentle touching, massaging etc. and onto sex proper.”
(Questionnaire participant 11)

Clearly the women’s experiences of their cancer and treatments had impacted upon their sexuality, sexual contact and intimacy, both throughout the treatment and survivorship phases. The next area which the women highlighted the effects of their illness on their relationships with their partners.

Impact /effect on the women’s relationships

All of the women expressed the ways in which their cancer experience had caused alterations in their relationship with their partner, in both negative and positive ways. The overriding issue identified was the change in the relationship dynamics, with all the relationship norms being ‘thrown into the air’ including the roles and responsibilities within the partnership. The women said that they found the changes in roles they experienced as being very distressing. They did not like the sense of being dependent on anyone, including their partner. What they saw as a previously equal relationship became unequal, causing many shifts and changes within the relationship, both in terms of physical roles but also in terms of the emotional interplay.

“Xxx was just such a rock as well as some other people in our circle family and friends. But she was, bore the brunt of the worry and the um I think the thing we because we’ve always been equal and very 50/50 sharing stuff out in our relationship..... but when she became a carer and I became very vulnerable... so, how, what does 50/50 look like in when something when one of you is a carer basically. One of you is very vulnerable”
(Interview participant 3)

One of the issues the women identified was the change in roles from that of partner /lover into cared for and carer. Whilst they acknowledged there was a need for their partner to take on more of the practical household tasks and some of the other caring responsibilities they found this difficult and furthermore found that these led at times to tension within their relationship.

“During my illness my partner took on most of the household type tasks – we had lots of help from our friends – who were great (we couldn’t have done it without them especially as my partner was working full time). It was hard for me, because I wanted things and how we were together to be the same, but it wasn’t possible.”
(Questionnaire participant 8)

“When I was having my treatment we carried on as much as normal as possible. But that wasn’t easy, so my partner ended up doing most of the household jobs etc. I was still able to do the joint finances bits. A lot of the time during treatment I felt really quite ill, so my partner took on the ‘carers’ role more - which caused her a lot of extra work - which was difficult as she was still trying to work full time. She didn’t say much, but I could tell from her non-verbal’s that she was tired and at times pissed off (not with me, but at the situation).”
(Questionnaire participant 10)

A number of the women highlighted the importance of trying to maintain good couple communication with their partners, to be able to talk about their concerns and also the day to day ‘normal’ life issues, as their illness didn’t take place within a vacuum.

“But what was good was we kept talking through it I was sort of trapped in that and um that our conversations was sort of dried up in a way at times. And that was very painful, I found that painful...”
(Interview participant 3)

“We talked things through, made more time for each other, took time out with each other and tried have always to keep our communication going over the years together, have worked through difficult periods.”
(Interview participant 4)

Interestingly, interview participant 3 above and her partner had used their mutual interest and use of writing as a means of breaching the silences which occurred. It also allowed them to broach the difficult topics such as their fears about losing each other that they had been avoiding.

It needs to be recognised however that some couples, in normal circumstances find it difficult to discuss things with their partners and be able to negotiate around their relationships. So add to this the burden of the women’s illness and treatments it is hardly surprising that some of the couples really struggled to maintain a solid relationship. In some instances, help with the problems they encountered and their relationship problems was sought and the issues resolved. Whilst for others the strain of their illness and treatments became too much for their relationship to overcome and unfortunately this led to the breakdown of the relationship and separation.

“We tried by ourselves at first, but things got a bit rocky so we went to see a counsellor - who was great. A lot of the problems we had were really little to do with the cancer etc - they were things we needed to sort out and maybe wouldn’t have done otherwise I think we may have split up if we hadn’t had help.”
(Questionnaire participant 8)

“My body changed radically from a healthy person who did yoga, walking, cycling and swimming to one which was unrecognizable. I became almost lame, temporarily, with chemotherapy. I was angry at the radical change in my life but also with my partner who was unable to cope with the demands it made on her. I think that she needed more support than I did in some ways....We had been living together for 9 years and were in a civil partnership and planning to buy a house together. Unfortunately either of us coped well with the aftermath of breast cancer and we separated within two years of diagnosis.”
(Questionnaire participant 3)

On the more positive side a number of the women discussed how their cancer experience had brought them closer to their partners and that their relationship was now stronger and more resilient than previously. In addition, the women also articulated the importance of the need for the partners to be given support as they felt they were often ‘left out’ of the support offered by both the NHS and other care and support providers.

“We’ve always had strong relationship, but now it feels stronger somehow, we have a different and deeper level of intimacy.”
“I think xxx needed more support in some ways than me. I tend to just get on with things and do things to distract myself. But she needs to everything possible to plan and cope, she phoned the helplines a few times but I know she wasn’t always happy with how they were with her, and she felt quite frustrated. She’s bit of a control freak really!”
(Interview participant 4)

The women found that their illness and treatments had really challenged their relationship in many ways. At times the experience improved their relationships, whilst at others it proved detrimental. All of the women experienced changes in their relationship dynamics, even on a ‘temporary’ basis, during treatment. Additionally, they had to renegotiate their relationship roles after completion of treatment.

The roller coaster ride of cancer

Not surprisingly many of the women described how from the time of their diagnosis cancer having taken over their lives. They identified several issues which are seen to contribute to a roller coaster effect. Firstly, was the anger they felt at having cancer and a desire to return to their life before cancer. Coupled with this was fear for the future and a fear of dying and leaving behind the people they cared about. In a sense ‘mourning’ the loss of their previously healthy self. Additionally, the women felt they were not in control of their situation and this added to their anger and frustrations. They felt that the cancer, treatments and hospital staff and

appointments were now in control and that they were now passive individuals to whom things happened. Much has been written about the 'need' to think positively and remain strong throughout the cancer experience, with the belief that this will improve the outcomes for the person with cancer. However, trying to do this was something that some of the women expressed as part of their roller coaster of feelings.

"I longed for my pre cancer life, longing for the past and also fearing for the future."

(Interview participant 3)

"I felt shocked and out of control – the cancer was not something I had any control over. All of the hospital appointments and treatment left me feeling even less in charge of my body - people /strangers were doing so many personal things to me and my body – it didn't feel like it was me anymore."

(Questionnaire participant 8)

"I'm a strong woman. I showed my family and my partner - I am strong. I will survive this sickness."

(Questionnaire participant 2)

Some of the women talked about how their concerns had been dismissed by health care professionals and that they were made to feel that they should be grateful for having their lives saved and not be concerned about 'minor' things, such as the impact on their body image, sexuality and sexual life.

".. But it's 'you're alive so f....off (laugh), so what are you looking at. But actually it, that matters how I feel about myself. Which then impacts on well do I feel about ever being physical with somebody"

(Interview participant 2)

"He was very dismissive and made me feel I was worrying about trivial things when he was about to perform a lifesaving operation. It was embarrassing."

(Questionnaire participant 5)

Fear of homophobia: relationships and interactions with healthcare professionals including sexuality not discussed by healthcare professionals

The impact of cancer on the women's sexuality, sexual health, relationship and together with their cancer experiences was immense and often devastating. In these circumstances the role of the health care professional is crucial to how the women feel and cope.

One of the main concerns the women expressed about their dealings with healthcare professionals was their fear of a homophobic response from the staff. This included anticipating issues with staff concerning the involvement of their partners in consultations, decision making and care. They reported experiencing some hesitation about 'outing' themselves to staff, which, given the history of homosexuality in the UK (outlined previously),

is hardly surprising. It was very heartening to find that on the whole these anxieties and fears were unfounded, with staff being respectful, non - judgemental and inclusive.

“The nurses etc. were really very good with us and gave us lots of information about how the treatments might affect our relationship and sexually. We weren’t expecting them to be so good with this, but all the way through they treated us like any other couple - it was good to see that our fears of meeting any hostility and having to do 'battle' with them were unfounded. I think it helped because we could say we were married - it might have been different a few years ago.”

(Questionnaire participant 11)

“Had really good care overall, didn't really have any 'gay' problems, they were on the whole great including us both. Just a few nurse and one doctor who were clearly uncomfortable - but good generally.”

(Questionnaire participant 7)

Unfortunately there were exceptions, with some women having negative with their health care professionals.

“The staff at the hospital didn’t give us any hint that this was something they would feel comfortable talking about – they were only just OK about my partner being with me for appointments, you could see that they weren't comfortable with us being a couple. We don't live in a big city, folks around where we live are rather old fashioned and less accepting of any type of difference - whether that is sexual orientation or race.”

(Questionnaire participant 10)

This experience appears to reflect the findings from both the expert panel /s (Chapters Four and Eight) and the first focus group of specialist cancer nurses (Chapter Seven). There are staff who do not feel comfortable discussing sexuality and relationships generally and with LGBT patients. The experiences of patients is a case of ‘pot luck’ in terms of their reception by practitioners. It also highlights the impact of the background and life experiences of the healthcare professional can have on the patient - practitioner relationship. This has to be a cause for concern as there are readily available practical packages such as PLISSIT (Anon, 1971), PLEASURE (Schain, 1988), BETTER (Mick, Hughes & Cohen, 2004) and DIRECT (Cawthorn, 2009), to help professionals be more at ease and to be able to facilitate discussions with patients. It would seem from this study that they were either unaware of these or had not seen the need to undertake specialist training to help them provide care in all aspects of the patient and family’s lives.

In addition, there were some women who perhaps due to their previous encounters with health care professionals did not feel comfortable disclosing about their relationship and were distrustful of healthcare professionals. This was sad to see, especially as some of these women reported having experienced problems in adjusting to their cancer altered lives and would perhaps have benefitted from some focussed interventions.

***“No way - we grew up in a time when being a dyke wasn’t accepted. My partner has a long history of mental health problems (severe depression) as a result of her parents sending her to a mental institution to get ‘corrected’. So neither of us really trust health professionals.”
(Questionnaire participant 9)***

Some of the women described how they had experienced the issue of assumed heterosexuality in their care journey. This was most often in relation to their pre chemotherapy assessment, the ‘tick list’ approach in regards to fertility section, where the potential for future wishes for children were bypassed when the women said they were in a same sex relationship.

***“... there were assumptions made about egg collection, when I said I was gay it was like OK onto the next question.”
(Interview participant 4)***

For this participant, this had felt dismissive, her sexuality was not worthy of discussion, and this in turn was a rejection and negation of her and her partner as women. This is not acceptable, at a time of great vulnerability they needed to feel secure and supported. It is hard to see how after this type of response, they could find the courage to raise deeply personal and intimate concerns.

Support groups and helplines

In the light of the above fear of homophobia the role of support groups, a concern raised by the women was the heterosexual focus of the cancer support groups or helpline help they had attended or accessed. In their experience the groups they had attended had not been ‘gay friendly’ with the result that the women did not find them to be ‘safe places’ to be open and fully discuss their concerns and worries.

***“.. it is where I really noticed the invisibility of being gay and that’s where some of that stuff.. there were all grannies they were all absolutely heterosexual and married and grand and families and I just thought I felt I stuck out like a sore thumb and then the psychologists are all young Asian girls they know their little tricks, but it’s their but again it felt both, both it just felt like we are a mile apart it was alright....it’s incredibly heterosexual it’s for yeah know it’s all very feminised it’s all about makeup, it’s all about particular type of what you wear and whatever”
(Interview participant 2)***

The experiences of these women appeared to echo those of other lesbian, bisexual and transgendered women in the scoping exercise undertaken recently by the Macmillan Cancer Support Care LGBT taskforce (Macmillan Cancer Support, 2016). In addition, it also appeared that some participants would have found talking about more personal, intimate issues with someone who was from the LGBT community. This also fits with the findings from the scoping exercise previously mentioned.

“It would have been good to have had someone gay to talk to about our intimate problems though - even on one of the helplines.”
(Questionnaire participant 7)

They had tried to contact specialist support services, but as with the hospital services they had not received the help they were seeking. They had been offered generic support but this had been superficial and they had not felt able to raise intimacy and /or sexuality with someone who they had felt was ‘*uninterested*’. This echoed the experiences of other women.

“The whole thing was about husband and two kids... but you had to be a traditional couple where he worked and she stayed at home... the new man wasn’t even accommodated ... never mind couples like us ...”
(Interview partner 1)

The absence of specific support also disadvantages non-traditional couples both heterosexual and those from the LGBT community. This situation has to be addressed if equity and informed choice are to be key components of care services, and for this to occur, the starting has to be education and training. This needs to encompass the patient and their partners /family because, as with the survivors, the analysis from the partner interviews and questionnaires produced a wealth of information which in areas such as this overlapped. It is important to recognise that the potential lack of support provided for the patient and partner because of their couple’s sexual orientation is likely to worsen as they move forward from diagnosis through the treatment phase. Therefore a good understanding of the partner’s experiences as distinct from that of the patient was seen as essential for the health care professionals providing care.

Findings: The Women’s Voices Being Heard and Presented – The Partners

The analysis of the partner interviews and online responses was undertaken following the same steps as those undertaken for the survivors, extracts of the process are presented as Tables (24) and (25) below with the resulting themes presented in Table (26)

Code and code descriptor	Original transcript/online response	Reflective initial comments
7 (a) Carers role = no time for self. 7 (b) Carers role = not able to see partner as sexual.	(QP1) p1 para 3 (QP3) p3 para 1 (QP4) p2 para 2 IP 1 and 2	Partners experiencing a loss of self & sexual closeness.
8. Guilty feelings when thinking about own needs. Partners needs paramount.	(QP1) p1 para 3 (QP 40 p2 para 2 IP 1	Partner's loss of self & own needs as important. Partner vulnerability.
9. Change in relationship dynamics, power within the relationship.	(QP 1) p2 para 1 both IP 1 & 2	Same as heterosexual literature, commonly found changes in relationship dynamics – the original 'relationship fit' challenged.
13. Staff didn't make them feel safe.	(QP1) p2 para 4	The 2 elements – this and below are linked – HCP's need to consider this when dealing and building trust/confidence of patients.
25. Loss of self - identity (became just the partner of the cancer patient & carer).	(QP4) p2 para2	Partner's loss of self.
24. Recognised the importance of being sexually intimate as 'limited life' together.	(QP4) p2 para 1 both IP 1 and 2	Cancer challenging the couples beliefs in being together forever, more important to express feelings for each other through sex. Importance of sexual intimacy to make people feel human & alive (link to previous literature). Changed /sharpened focus on what is important in life. Plus look at the Patient questionnaires.
25. Loss of self - identity (became just the partner of the cancer patient & carer).	(QP4) p2 para2	Partner's loss of self.

Table (24): Extract of initial unit coding – Partner interviews and online responses.

Code/code descriptor	Original transcript/online response	Reflective initial comments	Emergent theme
Carers role = no time for self. Carers role = not able to see partner as sexual.	(QP1) p1 para 3 (QP3) p3 para 1 (QP4) p2 para 2 IP 1 and 2	Partners experiencing a loss of self and sexual closeness.	Loss – multiple types.
Guilty feelings when thinking about own needs. Partners needs paramount.	(QP1) p1 para 3 (QP 40 p2 para 2 IP 1 and 2	Partners experiencing loss of self & own needs as important. Partner vulnerability.	Loss – multiple types.
Change in relationship dynamics, power within the relationship.	(QP 1) p2 para 1 both IP 1 and 2	Same as heterosexual literature, commonly found changes in relationship dynamics – the original 'relationship fit' challenged.	Change in relationship dynamics, power within the relationship. Importance of couple communication.
Staff didn't make them feel safe.	(QP1) p2 para 4	The two elements – this and below are linked – HCP's need to consider this when dealing and building trust/confidence of patients.	HCP's lack or don't use therapeutic relationship building skills
History of past abuse = difficulty trusting.			HCP's lack or don't use therapeutic relationship building skills
Recognised the importance of being sexually intimate as 'limited life' together.	(QP4) p2 para 1 both IP 1 and 2	Cancer challenging the couples beliefs in being together forever, more important to express feelings for each other through sex. Importance of sexual intimacy to make people feel human & alive (link to previous literature). Changed / sharpened focus on what is important in life. Plus look at the Patient questionnaires.	Change in relationship dynamics, power within the relationship. Importance of couple communication.

Table (25): Extract from searching for connections across emergent themes – Partner Interviews and online responses.

Overall, five main themes were generated and these have been identified in Table (26) below each of these themes will be explored in the following section.

Loss - multiple types.
Changes - multiple types - relationship roles, dynamics, couple communication and views on life. Importance of couple communication.
Fear of homophobia by HCP's and HCPs openness re: sexual orientation.
HCP's lack or don't use therapeutic relationship building skills.
Lack of LGBT specific information and cancer support organisations failing to recognise the needs of diverse relationships.

Table (26) Partner interview and online responses: themes.

Loss - multiple types

One of the major issues identified by the lesbian partners was that of loss. For these women loss took a multitude of forms. Firstly, many of the women had a fear of losing their loved one and this took major priority in their lives at that time, certainly over any need to be sexual.

"I came close to losing the person I love, they are so important to me. This took priority over everything else. It made me re - evaluate what was important."

(Interview partner 1)

"I don't want to think about life without her!"

(Questionnaire participant 3) - the couple had been together for over 45 years

Another issue identified by some of the women was that they felt that the cancer and treatments had changed everything in their relationship, with them feeling less close to their partner than before the couple's experience of cancer. Linked to this, these partners felt resentful of the changes in the relationship and the situation.

"Her illness has changed everything, we were and still are close, but it's not the same as all our previous years together.....which I can't help resenting, if it was going to be short lived I think I would cope better."

(Questionnaire participant 3)

Not surprisingly, like the survivors the partners identified the loss of sexual closeness in their cancer experience. They had missed full sexual contact in the treatment phase, watching as their partner experienced sickness, tiredness and the ongoing effects of cancer which was very stressful.

"Yes, when she was having the cancer treated we didn't have any sex, it would have not been possible. We didn't have much intimacy generally, both too tired and stressed out."

(Questionnaire participant 2)

An additional issue for partners was the impact of undertaking the carer's role and the effect this had on the couple's sexual intimacy.

For most of the partners this was felt only in the short term, although one of the women reported that it continued to affect the way in which she saw her partner.

"I undertake a lot of her physical care, which again isn't really helpful to feeling close /intimate - I just see her now as an invalid who is dependent on me not as the sexual and sexy person she used to be."

(Questionnaire participant 3)

It is recognised that male partners of patients with life threatening or long term conditions often find the transition to and from care giver to 'sexual partner' difficult (De Vocht, 2011) and that they sometimes struggle with the physical aspects of care. However, it has not been recognised previously that the situation might be the same for women in lesbian relationships.

It appears that this may be due to the expected gender roles, with women being seen as ‘*naturally nurturing*’. However, the women in this study clearly demonstrated that these gender stereotypes are unhelpful and can lead to a lack of tailored care provision by health care professionals - seeing all women as able to meet all aspects of their partners care needs.

Some of the women said that they had themselves at times suffered a sense of a loss of identity, through becoming just the partner and carer. This was accompanied by a sense of loneliness and at times, as the women below reported mixed thoughts and emotions about the ‘rightness’ of their feelings.

“Just became the carer - doing everything for her and little time for me. Felt guilty if I thought about my needs as hers so much more.”
(Questionnaire participant 1)

“With everyone, including the hospital staff I felt I was her partner - I lost my own identity. At times I felt angry about this - who was there for my needs? Of course I would then feel guilty for thinking and feeling like that (I’m always good at beating myself up).”
(Questionnaire participant 1)

The above demonstrates that there is a clear need for HCP’s and support organisations working with patients with cancer to recognise the care and support needs of their partners. The challenge here may be one of funding and resourcing - especially with ‘over stretched’ clinical areas, the priority being rightly seen as the person with cancer.

Changes – multiple types - relationship roles, dynamics, couple communication and views on life

The major change in the couple’s relationship dynamics was the alteration to the household roles undertaken. Whereas these had previously been fairly equally split between the couple, during the treatment phase not surprisingly these all fell to the partners. Whilst they didn’t mind this alterations these did leave them feeling very tired. As previously identified by some of the survivors the couples did have a lot of support from friends and families, especially with the practical ‘chores’ including helping to take partners to and from hospital treatment appointments.

“It was difficult at times especially during her treatment all the household stuff seemed to fall to me I tried so hard to there for her in all ways to do everything but I couldn’t I had to work as well. Our friends and my partner’s family were great they helped so much. They even set up a hospital appointments and cooking rota.”
(Interview participant 2)

As would be expected during such difficult times partners also reported some communication problems. Several of them talked about how they had found themselves arguing and in conflict

with their partner, something which was unusual for them, this had left them feeling hurt and vulnerable, and at times 'frightened' by the altered situation. Perhaps as a result of repeated disagreements, some of the partners reported avoiding difficult conversations, not feeling able to share or talk about their worries - especially in relation to their fear about potentially losing their loved one. They were afraid of upsetting their partner, but as the interviews revealed their partner was doing the same thing, this led to a collusion of silence and an increasing distance between the couple. Other partners, whilst they found talking difficult they were able to do so, which helped keep their relationship on an 'even keel'.

"... and also we found talking about what was happening difficult. At times we argued - which was new to us. It was hard."

(Questionnaire participant 1)

"When she was having the tests and treatment at times things got a bit tense - we 'bickered' more than usual - I think we both felt the strain of it all. We are lucky that we have always been able to talk about how we feel - although sometimes we have to really work at this as we both clam up. But on the whole we were and are able to talk."

(Questionnaire participant 4)

For some partners the power dynamic within the relationship changed, especially during the treatment phase. With the 'locus of power' shifting between the woman with cancer and their partner, dependent upon what was happening at the time and the individuals own emotional state. As with the survivors, the partners talked about having to seek for a new equality within the relationship both in the short and long term.

"Like I said, all changed. We had an equal relationship 'til then. Better now but not back to how it was."

(Questionnaire participant 1)

"xxx has always been the bossy one in our relationship, but when she was ill this changed a lot. She became vulnerable and rather dependent, which she didn't like. I had to take on a more active role - which suited me. Now she is better we are having to learn a new way of being together..."

(Interview participant 1)

The partners also found that more open communication, plenty of talking and taking things slowly together, helped them get their 'sexual intimacy back on track' after the treatment phase had been completed. Some of the women had worried about physically hurting their partner, so were hesitant, but if they had been able to talk about it they had been able to overcome the difficulty.

"We have always though been very touchy and huggy with each other and this didn't / hasn't altered. I was at times a bit hesitant to give my partner a hug - in case I hurt her, but I learnt to 'ask' if it was OK and she learnt to let me know if she didn't want to be touched at all."

(Questionnaire participant 4)

The woman above went on to say:

“Actually since all the treatment has finished we have been more sexual - from my part because I realised how important this type of intimacy is for me and us, and maybe she won’t be around forever (as we once thought) - so making the most of the time we have together.”
(Questionnaire participant 4)

This highlights how having gone through a cancer experience does not always have a negative effect on the couple’s sexual relationship. Indeed they can, as this couple did find new ways of ‘being’ sexually together, which can enhance what they have together.

The women described how the experience had brought them closer to their partner, and as with the participant above it had shown them the importance of creating time for each other and had made them reassess what was important in their lives. A reflection of experiences of other couples when their relationship is challenged by any serious life even (Goodhart & Atkins, 2012). It is seen as essential for professionals to understand the adaptation process and to give appropriate individualised support.

Fear of homophobia

As with the survivors, the partners experiences with health care practitioners was varied. Whilst most of the women feared that they would encounter homophobia from the staff, this did not prove to be the case for most of the partners.

“The staff were really good and I think if we had needed to they would have looked to be helpful I know that my partner found the staff very helpful through the whole experience and was able to talk to them when she needed to. Our relationship didn’t appear to bother them and we were always treated as a couple.”
(Questionnaire participant 4)

“The care we had all the way through was excellent and we didn’t really have any problems, you know about the gay thing. Our GP especially was great, she offered good support to both myself and xxx, however, there were a couple of staff at the xxx hospital who were clearly not happy about our relationship. One of them, despite my asking her not to, told xxx’s daughter about her diagnosis before we had chance to talk to her. I was really angry with her!”
(Interview participant 1)

The experience outlined by interview participant 1 clearly demonstrated a total negation of her role by the health care staff with potential damage being done to her relationship with her partner’s daughter in the longer term. As relationships with children from previous marriages or relationships are known to be sometimes difficult within same sex relationships (Berzon, 1997), this demonstrated a lack of awareness of the potential family dynamics by the health care staff concerned.

In the light of this it was not surprising that some of the partners who had either previously experienced homophobia from health care professionals or were too fearful to risk “outing” themselves to staff. It was sad to that they closed themselves off from potentially being offered and given appropriate support by the health care practitioners.

***“... - but I am scared to be open with them as I have had very bad experiences in my past with health care workers and their homophobic attitudes.”
(Questionnaire participant 3)***

Given the history of homosexuality in the UK, it is not surprising that some lesbian women are concerned about the response of health care practitioners. The participant above had also identified that she had been subjected to conversion therapy in her youth, which would explain her reluctance to seek help from healthcare professionals.

One of the women stated that she and her partner had experienced sexual problems following her treatment for cervical cancer. However they had not felt able to discuss their problems with the staff, who had given her partner some vaginal dilators (post radiotherapy), with no information about what they were for or how to use them.

***“No, didn't talk to them, they didn't seem interested in that sort of things. Yeah, they gave her some dilators but not why and how to use them, didn't ask about whether she would need / have fanny sex or not. Didn't feel able to ask 'cause we weren't really open about our relationship and they never bothered to check.....It would have been good if we could have been more open, but the staff didn't make us feel safe - and you know, we both have abusive pasts so trusting is difficult anyway.”
(Questionnaire participant 1)***

In addition to the lack of instruction, it was clear that because of their past experiences these women would need to feel safe with the staff before discussing any issues or problems. This clearly illustrates the impact of past experiences have on patient - practitioner relationships. This demonstrates the clear need for health care practitioners to have an awareness of the impact that the previous life experiences of lesbian women can have on those with whom they need to develop a therapeutic relationship.

Linked to these areas, the women also identified that despite determined searching they had been unable to find appropriate lesbian specific information available either via the NHS or cancer support organisation. As mentioned previously (page 101) they had contacted the cancer support organisations, and were keen to express how they had felt when they found them failing to recognise the needs of diverse relationships.

“I'm the type of person who needs to get information and understanding of a situation to feel able to control and cope with difficulties. So, for me it would have been useful if, when I

contacted the xxx helpline they had been able to recognise and have knowledge about LGBT relationships. They didn't so I was left feeling let down and frustrated, I felt so vulnerable at the time and they really didn't help."
(Interview partner 1)

Again the distressing experiences of these partners appeared to echo those of other lesbian, bisexual and transgendered women in the scoping exercise undertaken recently by the Macmillan Cancer Support LGBT taskforce (2016).

Health care practitioners and the therapeutic relationship

Issues regarding the women's experiences with health care practitioners also need to be reviewed. The partners reported the need for the practitioners to have both a better /wider understanding of the diversity of the patients they are caring for and better communication / interpersonal skills. As with the survivors, they found that the staff were technically and clinically competent, but often lacked the human skills needed to make them feel comfortable and part of the care partnership.

"Technically I couldn't fault them, they were excellent. But I /we were made to feel like a little cog in a big wheel, a bit like being on a conveyor belt. Most of the nurses were pleasant enough, but they lacked the gentle, human touch that I know myself and xxx needed – especially when things got tough."
(Interview partner 2)

The partner above identified two points worthy of consideration. Firstly, is the anonymity experienced, with feelings of being 'one of many' within the healthcare system. Whilst it is true that the number of patients being seen by the NHS cancer services is large, there should be no reason for patients and significant others feeling that they, as individuals 'did not matter' to those caring for them, that they were just 'one of many'. The codes of practice for both medical and nursing staff (GMC, 2013, NMC, 2015) make it explicit that practitioners are required to view and treat each person as an individual, with unique needs. Hence offering appropriate levels of time and addressing the patients individuality is seen as of central importance.

Secondly, is the issue the 'lack of the human touch' viewed as the staff demonstrating a lack of kindness and compassion, a serious concern as patients have identified compassion as the most fundamental aspect of nursing care (Patients Association, 2011, Jackson & Irwin, 2011). Furthermore, whilst the women in this study represent a small sample, the lack of kindness and compassion in care is seen as significant and an indicator of a systemic failing within our healthcare service. Thus, reflecting the findings of the Mid - Staffordfordshire 'Francis' report

(2010), where a lack of kindness and compassion was one of the major failings in care identified.

Discussion and Summarising Of The Findings From This Phase Of The Journey With Implications For Practice And Education

In the introduction to and rationale for the study it was stated that there was an extensive evidence base regarding the impact of cancer and treatments on the sexuality, sexual health and relationships of heterosexual women who experience cancer. Whilst the corresponding evidence base regarding lesbian and bisexual women was extremely sparse, and in terms of the experiences of lesbian and bisexual women in the UK appeared to be absent. In discussing the findings from the exploration with the lesbian women and partners, areas of convergence with and divergence from their heterosexual counterparts will be identified. In addition, as this study also incorporated the potential impact of the women's sexual minority status on their experiences of healthcare provision in terms of the impact of cancer and treatments on their sexuality, sexual health and relationships these will also be discussed, the implication for practice being identified.

Convergent experiences with heterosexual people affected by cancer (survivors)

As with their heterosexual counterparts the women experienced an impact on their sexuality and sexual health (including psychosexual health) in a number of ways. The negative impact on the women's body image, feelings of attractiveness and femininity were experienced, resulting from surgery, chemotherapy and adjunctive therapies. Numerous studies demonstrated this negative impact on heterosexual women, commonly in relation to treatment for breast cancer (Fobair & Stewart et al, 2006, Emillee, Uusher & Perz, 2010, Bakht & Najafi, 2010). Similar to the experiences of heterosexual women the women in this study identified the importance of their partner's response to their altered body image, those women whose partners were positive and supportive experienced better psychological adjustment than those whose partners were less positive or supportive. In addition, some of the women said that they felt dirty and unattractive and couldn't understand how their partners would want to be sexually intimate with them. This was especially experienced by the women who had undergone stoma surgery, again reflecting the feelings and anxieties expressed by the heterosexual women (De Silva, Hull & Roberts, 2008, McIntosh, Pardoe & Brown, 2013, Milbury & Cohen et al, 2013).

The effects of the treatment induced menopause were also identified, with the women experiencing vaginal dryness and dyspareunia. This was coupled with altered body sensations and sexual feelings, leading to difficulties with sexual arousal, as with those in the

heterosexual literature (Fobair & Stewart et al, 2006, Emillee, Uusher & Perz, 2010, Sadovsky & Basson et al, 2010). These changes had led the women and their partners to explore 'new ways' of being sexual together, in some instances actually widening their sexual repertoire and improving their sexual intimacy. Viewed as a positive consequence of their cancer experience.

Where the women were not in a relationship they identified their fears and reluctance to either seek or enter into a new relationship. As with heterosexual women, these women found they were unwilling to expose themselves to potential rejection when they were already feeling emotionally vulnerable (De Vocht, 2011). With so much focus being placed on the impact upon the coupled relationship, in practice this is an area that women often wish to explore especially in terms of when to tell a future 'partner' that they have had cancer and how to 'protect themselves emotionally' from any rejection and hurt. This is certainly an area worthy of exploration by any practitioner working with these vulnerable women in terms of useful strategies for the patients to have in their own emotional and relationship 'toolkit'.

Sexuality (including sexual orientation) and sexual intimacy were not seen as important /a priority at the time of diagnosis and during the active treatment phase. Like their heterosexual counterparts, the women identified the focus was principally on 'beating' the illness, together with the endless round of hospital appointments, tests and treatment sessions. Sexual intimacy not being 'on the agenda' due to the side effects of their treatment regimens (Fobair & Stewart et al, 2006, Emillee, Uusher & Perz, 2010, De Vocht, 2011). The heterosexual literature has shown that there are clear differences between men and women around the role of sex within their intimate relationships. With men said to express their love and intimate feelings through sex, whilst women can show these emotions through other non-sexual means, hence the 'meaning of sex' is said to be different between the genders (Rolland, 1994, Carlson et al, 2000). One would therefore expect that within lesbian relationships the 'meaning of sex' would be different, modelling the identified female model. However, this wasn't found to be the case in this study, with the women saying that they pushed their partners away if they thought that they wanted sex.

Women within both the heterosexual literature and this study said that they either gradually resumed sexual activity with their partners, sometimes sex taking on a 'new form' or unfortunately, never resuming their sexual relationship at all. It has previously been shown, that for some people illness and treatment can legitimise their wish to cease sexual activity with their partner (Wig, 1973, Shah & Stein et al, 2009), it is suggested that this may also be the case for some of the women in this study. It is also suggested that this legitimisation needs

to be taken into account when working with a couple who are experiencing sexual distress as a result of their cancer experience.

Surprisingly given the expected differences in relationship dynamics anticipated within a same sex female relationship in terms of the relationship experiences, the majority of the experiences of the women in this study reflected those previously identified in the heterosexual studies (Holmberg et al, 2001, Fitch & Allard, 2007, Kadmon & Ganz et al, 2008, Kinsinger, Laureneau et al, 2011). Not surprisingly, the cancer diagnosis and treatments had led to the usual roles within the relationship being thrown into disarray, with the partner and friends taking on additional roles and responsibilities. Leaving the women feeling distressed by the changes and increased dependence on others, impacting negatively on their self-esteem and self-image. In addition, more frequent relationship talk led to less relationship distress and better relationship and general adjustment over time. With the couples who were able to talk together about their concerns and feelings being better placed to come through the cancer experience with a strong or stronger relationship seen as a positive effect of cancer (Manne & Badr, 2008, Kinsinger, Laureneau et al, 2011).

Several studies have previously identified that how a couple deal with cancer is partly influenced by their coping styles and roles within the relationship prior to the diagnosis (Weijmar Schultz, 1992, Sormonti & Kayser, 2000, D'Ardenne, 2004). These studies also found that established relationships are less vulnerable to distress and breakdown than less stable or newer relationships. This was also found to be the case for the relationships of the women in this study. Furthermore in keeping with the findings (Holmberg et al, 2001, Kinsinger & Laurenceau et al, 2011) the experiences of having cancer exacerbated existing problems and unsatisfactory relationships leading some women to end their relationships, whilst for others the stress of dealing with cancer and treatments placed too much pressure on the partner, who chose to end the relationship.

Much emphasis has been placed in the information given to patients and the prevailing culture within cancer care and the cancer experience on the need for positive thinking and adopting a 'battling' position (Sulik, 2012). This was certainly an issue identified by the women in this study, especially in terms of how they wished to be viewed by the friends and families. However, several women said that they had a 'longing' for their pre - cancer self, mourning the 'loss' of this person. At times identifying the wish not to have to be strong and positive, with feelings of low mood and /or depression, whilst at the same time feeling guilty for not feeling positive and having the 'fighting spirit', reflecting literature such as the 'Pink ribbon blues' (Sulik, 2012).

In terms of their experiences of the healthcare system the women in this study had a number of shared experiences with their heterosexual counterparts. One of which was the feeling that they were not in control of their situation and that hospital staff and appointments were now in control, that they had become individuals to whom things happened (de Vocht, 2011, Goddhart & Atkins, 2013). They identified feeling that they were part of a big machine or conveyor belt and after treatment has been completed being ejected from the system, leaving them feeling isolated and missing the professional support and patient comradery they had experienced during their treatment phase (de Vocht, 2011). These feelings and experiences have been recognised within the 'cancer care community' and led to the establishment of, many survivor groups (Macmillan Cancer Support, 2016). However, the women in this study identified that the heterosexual focus of these support groups was inhibiting, finding the groups to be unsupportive. Additionally, the women identified that their concerns and problems related to their sexuality and sexual health were not seen as important by healthcare practitioners (they should be grateful just to be alive). Indeed the healthcare staff did not address these areas with them at all, instead focussing only on the clinical aspects of treatment. This clearly reflects the studies reviewed in the supporting information for this study and the findings from both the expert panel and specialist cancer nurses elements of the study (to be discussed in Chapters four, eight and nine).

Divergent experiences from heterosexual people affected by cancer (Survivors)

In terms of the impact on body image, some of the women expressed surprise that this was an issue for them as lesbian women as they had assumed that it would be less important within a lesbian relationship. Indeed Boehmer et al (unpublished) and Fobair & O'Hanlon et al (2001) had found lesbian women experienced less problems with their body image, being more comfortable showing their bodies to other people than their heterosexual counterparts. This perhaps reflects the changes in the views in society generally around the importance of the 'perfect' body (Bolton, Lobben & Stern, 2010). In addition it may also reflect the personal vulnerability of the individual women in terms of their overall pre cancer attractiveness. Several of the women identified the impact of their cancer on their self and sexual identity, with their previous views of themselves as strong 'Amazonian' women being severely challenged. Furthermore, several identified changes in the way in which they viewed their place in the world (either transiently or permanently), this had an impact on their overall adaption to being a cancer survivor.

As identified previously, many of the women pushed away their partners due to fear of sexual intimacy. However, these women also identified that as they had no physical (non - sexual) contact with their partners they missed the closeness within their relationship and as a result

felt lonely and isolated. Those couples who remained non - sexually intimate during the treatment phase found it easier to become sexually intimate afterwards during the 'survivor phase'. During this period however, some women expressed they needed to negotiate sexual intimacy with their partner, they needed to take control this was especially evident where the sexual desire of the women was effected by their cancer experience.

In terms of their relationships the main difference the women expressed was the change in the power dynamic within their relationships, this becoming unequal and them struggling with this alteration. In addition, they identified that they struggled to re-establish a more equal relationship post treatment and within the 'survivor period'.

Convergent experiences from heterosexual people affected by cancer (Partners)

As with their heterosexual counterparts and the limited information regarding lesbians, the partners of women in this study found thoughts of being sexual with their partners unimportant and frivolous, especially at the time of diagnosis and during the treatment phase. In addition, they also identified being frightened to touch their partner as they were worried they might hurt them through inappropriate touch (Holmberg 2001, Pitceathly & McGuire, 2003, Fobair et al, 2001, Arena & Carver, 2007, Palm & Friedrichsen, 2008, De Vocht, 2011). The partners were also far more worried that their partner could die, leaving them by themselves than thinking about being sexually intimate.

In terms of couple communication, several of the issues /themes identified by the partners in this study mirrored the findings from previous, heterosexual studies. This included, alterations in communication styles leading to increased couple conflict and avoidance of having difficult conversations. The changes in the relationship dyad /couple preventing them from being able to mutually discuss their feelings about grief, loss, potential reoccurrence and potential death led both partners feeling left alone with their fears (Ganz & Rowland et al, 1998, Sormanti & Kayser, 2000, Holmberg, 2001, Pitceathly & McGuire, 2003, Arena & Carver, 2007, Palm & Friedrichsen, 2008, De Vocht, 2011, Goodhart & Atkins, 2011). As with the partners in De Vocht's (2011) work, some of the partners in this study, reported the experience that 'things were never the same again' that somewhere along the path from diagnosis through treatment they had lost their soulmate and sexual partner. Indeed the partners had identified and reported that there were continued alterations in their couple communication post treatment. As a consequence, in order to 'protect' their partner they chose to avoid conflict over minor issues, unfortunately, as they had not explained why they had changed their approach and

way of communicating, this led to the couple having more substantial arguments as both parties 'bottled up' their feelings (Holmberg, 2001).

Reflecting further on the findings from the previous literature, the partners in this study had struggled alone (without professional emotional support), they had identified changes in relationship roles, and found themselves unexpectedly becoming the carer and no longer the lover (Palm & Friedrichsen, 2008, De Vocht, 2011). From the heterosexual studies, male partners identified that they were able to provide instrumental support, but struggled to provide the emotional /psychological support partners needed (Holmberg, 2001, Goodhart & Atkins, 2011, De Vocht, 2011). However, the partners in this study felt that they were able to give their partners support on a more holistic basis, although this took a toll on them. Nevertheless, this mirrors the lesbian women in Fobair's (2001) study, who found that their partners were more likely to be caring, loving, listen and be relied upon to help with daily tasks. It also illustrates that for the partners this was to some extent a lonely road, as the 'patient' tended to find the treatment all-consuming and thus did not consider the impact it was having on their partner.

Divergent experiences from heterosexual people affected by cancer (Partners)

Reflecting the experiences of the survivors, several of the women found that their cancer experience had in the end, brought them as a couple closer together. They also identified that where more open communication had been possible, this had led to them as a couple to be able to re-gain their sexual intimacy and put themselves as a couple 'back on track'. In addition, not surprisingly, the partners also identified a fear of homophobia by health care staff, although this not always been borne out in reality. They did however report finding a total lack of LGBT specific information and support being available to them, they also stated that they experienced a lack of the 'human touch' and that they had found poor communication skills being displayed by the health care professionals. Unlike the women in Fobair's (2001) study, not all of the partners felt able to be relied upon to help with the daily care tasks, this challenges the gender stereotypes regarding caring roles.

Implications for practice and education

The commonality of many of the experiences of the women with their heterosexual counterparts has clear implications for practice education. As previously outlined and discussed the healthcare practitioners do not feel confident and competent to undertake addressing sexuality, sexual and relationship health with their patients. It is therefore seen as essential that practice education is developed and provided to staff in order for this situation to be rectified. This is seen as essential not only for lesbian women, but also for all individuals

affected by cancer. In addition, the women in this study identified that the practitioners they had encountered whilst clinically competent lacked the 'human touch' expected. It is therefore, also seen as crucial for the 'softer skills' to be addressed within healthcare practitioner education.

Reflective research journal entry and reflexive comments:

*'Although areas of similarity with the heterosexual literature, prior to this study there was little or no evidence as to whether this would be the case. This counts as new knowledge c/o lesbian women, because based on the literature (repeatedly) studied and searched there had been **no such study as this before, certainly not in the UK looking at or exploring the impact of cancer and its treatment on the relationship and especially partner experiences.**'*

'The views, experiences and opinions of the expert panel were useful to 'paint the wider picture', but it is crucial for the development of services for this group, that the whole picture is included in service delivery and for that there needs to be a conceptual framework that professionals can use to guide their practice as they work with these vulnerable women. For the professional 'at the chalk face' this needs to be realistic and to recognise their skills, expertise and gaps in competence. For this I needed to seek out CNS's and other frontline cancer /oncology staff and to explore with them how they saw their role and practice. I wanted to take them with me on the journey - that way they would have some ownership of what is developed and can feel able to 'buy into it'

Reflexive comments:

- As a lesbian I had assumed that I had an insider position with the participants - that this would facilitate ease of access to a community known to be difficult to reach. I was wrong in this! I did not make my sexual orientation known to potential participants in the recruitment /advertising information. I may therefore have been viewed by potential participants as another heterosexual researcher wishing to explore the 'differences' between them and heterosexual women - leaving them worrying about potential pathologising of their relationships and experiences.
- Checked potential influence of own past in regards to the format and content of the interviews, the website development and online questionnaire format and content with my supervisors prior to both ethics application and implementation.

- Scrutiny and justification by /with the ethics committee.
- Utilising my reflective dairy throughout all elements of the 'data collection' and analysis to check out any potential bias or 'intrusion' of my personal 'baggage'.
- During the analysis of the transcripts adopted the phenomenological principles to try to ensure the voices of the participants were heard and represented (including 'outlying' experiences). As a lesbian I had to be careful not to try to speak for the research participants who although also lesbians had different personal histories and experiences from myself.
- Revisited existing literature - both sexuality in healthcare in general and cancer specific, to both inform the interview schedule and online questionnaire format, also returned to during the analysis of the interview transcripts and questionnaires.
- Discussed this analysis with my supervisors to check for any personal bias, seen as especially important with these participants.

During the analysis of the interviews and questionnaires it had become clear that the women had been seen by a variety of health care professionals - not always those in the more senior positions. It is therefore important that I explore the experiences of more front line practitioners to gain a clear picture of their experiences of working with patients from the LGBT community.

Chapter Seven: Journey Phase Three (B) - Phenomenological focus group with cancer clinical nurse specialists

Positionality for specialist cancer nurse focus group.

As previously (prior to the expert panel workshop), I felt it appropriate to review my position as an insider or outsider to the group i.e. the degree of my connection to the group I was 'studying' (Merriam & Johnson- Bailey et al, 2001, Bourke, 2014). In this instance a group of cancer nursing practitioners. I had several aspects in common with the practitioners i.e. my nursing background, my interest in cancer care and my ongoing practice as a therapist (I wasn't 'just' a researcher with no practice background). In these respects I could be viewed as an insider, however, despite wishing to work with them as a researcher my position within the university as a senior member of the academic and teaching staff could have influenced their perceptions of me. In this regard, they may have held their own perceptions and 'world view' of who and what I was which may have implications for how they work with me, in these respects I was a potential outsider. I needed to be cognisant of this as I collected their experiences and analysed their discussions.

Reviewing the data analysis from the expert panel, it was seen as essential to meet with and explore the issues with another sample of professionals, to elicit the experiences of practitioners working at different levels of practice than those represented by the expert panel. Therefore, a purposive sample of 10 - 12 specialist cancer care nursing practitioners, recruited from students attending post registration cancer and palliative care nursing programmes at a UK University, were invited to participate in a focus group interview - prior to and after the analysis of the data sets and their recommendations for practice.

The Aims For This Phase Of The Research Study Were To Identify Key Aspects, For Clarity These Are Listed As:

- Assessment and interventions undertaken by the specialist practitioners with all female patients including lesbian and bisexual women, in regards to their sexuality, sexual health and relationships.
- Explore any factors which may positively or negatively affect the specialist practitioners talking to their patient's about the potential impact of cancer and treatments on their sexuality, sexual health and relationships.

- Discuss the strategies which would help the practitioners feel more comfortable in discussing sexuality and relationship issues with patients generally. And more specifically with lesbian or bisexual women and their partners.
- Identification by the practitioner's suggestions of useful content to include in a 'training package' to help develop practice in this area, together with the format of such a 'training package'.

Data collection

Focus group

Focus groups are a well-established research method, which have been frequently been used within both healthcare and education (Lanshear,1993, Cohen, Manion & Morrison, 2000, Shankar, Selvin & Alberg,2002, Jefford, Karchalios & Pollard, et al,2008, Smith, 2011). They involve an organised discussion with a selected group of individuals to gain information about their views and experiences of a topic.

Cohen, Manion & Morrison (2011) also suggest that focus groups are useful in conjunction with other forms of data collection, as they can be triangulated with other findings to make a study more methodologically robust. One of the advantages of focus groups is that they increase participants interactions, which results in new thinking about a topic and produces more in depth discussion (Krueger & Casey, 2015), which was seen as essential when developing and evaluating the conceptual framework. In addition, focus group facilitation provides rich information from the observation of the non - verbal behaviour of the group (expressions, attitudes and intensity of conversation).This was viewed as important, as this study addressed a sensitive area of practice and the participants may not have felt comfortable discussing their practice in this area with their fellow nursing colleagues without skilled facilitation. This had previously been demonstrated both within the literature and the experiences with the expert panel earlier in the study.

As with all methods, focus groups are not without their disadvantages. One of which is the risk that without strong facilitation that one or two participants may dominate the discussion and /or take the discussion off track. It was anticipated that due to the facilitators experience of managing group processes this difficulty would be appropriately managed. It is argued that focus groups findings lack generalisability to the larger population as the group is not a random sample (Liosselti, 2003). However, prior to developing and evaluating the conceptual framework it had been decided that a group of specialist cancer nurses would be

representative of the healthcare professionals most likely to be working with the lesbian and bisexual women throughout their treatment journey. As with the interviews with the lesbian women, the focus group facilitation was underpinned by the phenomenological approach, influenced by feminist research principles.

Sample and inclusion criteria

Specialist oncology and palliative care nurses attending post registration cancer care nursing programmes at a UK University between 2015 - 2016. An overview of the study together with the aims of the focus group, plus participant information sheets and consent forms were provided to the group by the researcher three days before the optional focus group took place. This enabled the potential participants the opportunity make an informed choice about participating the focus group.

Conduct of the focus group

Following the approach advocated by Litosselti (2003) and Kruger & Casey (2015) who suggest group sizes of between 8 – 12 participants, the focus groups consisted of 12 specialist cancer nurses. The focus group took place at a U.K. University in a comfortable and private room and lasted 1 - 1 ½ hours, reflecting the advice of Morgan (1997) who suggests a duration of 1 - 2 hours.

When conducting the focus group the guidelines and approach advocated by Smith (2011) were adopted. The focus group commenced by establishing the focus of the session, stating its purpose and length, together with encouraging trust in order to develop an open discussion, by outlining the groups ground rules, including confidentiality, allowing people time to speak and keeping to task. In addition, the facilitator reminded the group that the session would be audiotaped and reassurance given regarding confidentiality and anonymity. The session then moved on to 'easy' initial questions to help participants engage with the subject before moving on to generating data by asking more precise questions for each topic area. Exploring behaviour or 'doing' questions before exploring attitudes (so crucial in this study), encouraging the participants to tell their stories of their experiences of engaging with the specific areas of practice identified. Finally, the session concluded with a summing up of the group discussion, taking stock and identifying the key points for the content and modality of the education programme /toolkit, together with a discussion of 'where next' for the study, programme / toolkit development and its 'roll out' into practice education.

Data analysis

Miles and Huberman (1994) suggest that central to data analysis in qualitative research is the process of making sense of what people have said, identifying patterns and understanding

meanings. Bryman (2008) identifies that a very common model for analysing qualitative data is thematic analysis, with Braun & Clarke (2006) arguing that through its theoretical freedom, thematic analysis can produce a rich and detailed account of the data. Two models of thematic analysis were considered, namely, Braun and Clarke's (2006) six stage process of data analysis and Krueger's (1994) five stage process of framework analysis. However, as the study was a phenomenologically inspired journey the data analysis process adopted for the analysis of the data set from the interviews and questionnaires with the lesbian women was utilised (see pages 89 – 92).

The focus group interview with a group of 12 cancer specialist nurses was undertaken in order to assess their current knowledge, experiences and attitudes in relation to women, especially lesbian and bisexual women's sexuality, sexual health (incorporating psychosexual health) and relationships.

As previously experienced with the phenomenological data analysis of the interviews with the lesbian women, the analysis commenced with **the reading of the data - gaining a sense of the whole**. This allowed for immersion in the data - thus giving an overall sense of the data, generating initial ideas of the substance of the focus group discussion. This was then followed by the production of **the initial codes**. Table (27) below offers an extract from this stage of the analysis.

Code	Description of code	Original transcript	Reflective initial comments
1	Effects of chemotherapy.	2. Yes, particularly with chemotherapy. 1. Why relevant to chemotherapy? 2 (a) Because there is a risk when having sexual intercourse to you & your partner during the seven days of treatment so it's something which should be discussed. 2(a) chemotherapy I think holistically we might look at the relationship that they've got, the support that they have got & yes bodily fluids, chemotherapy, fertility.	Recognise the importance/ place of impact of treatment on patient's sexuality. Especially in relation to the side effects of treatment – in physical terms.
2	Psychological impact – body image etc.	2(b) It's the psychological effects of chemotherapy as well, the side effects effect your physical being, your body image.	Recognise the importance/ place of impact of treatment on patient's sexuality – the psychological impact.
3	Vaginal dryness.	2.(b) maybe vaginal dryness and basically all those things. 2(j) she said she'd mentioned vaginal dryness to the consultant in the last appointment as bothering her.	Physical impact of treatment on sexuality / reproductive tract.

Code	Description of code	Original transcript	Reflective initial comments
7	Fertility issues/childbearing and cancer.	2(d) I think alongside that is the big issue of fertility as well. For some people if they know they can't have children, if that's what they chemo is going to do to them, they may not want to have sex. For woman it can make you feel, like not whole. 2. (d) I mean that if this was their plan, their life plan that this was going to be their next step in their life plan. Now cancers come along & the baby is not going to happen.	Impact on reproductive aspects of sexuality/sexual health.
10	Unsure when to address sexuality/sexual health in the treatment plan/journey.	2 (d) but are not sure how to be up for it and where to go to ask for information and at what point of the patients journey is it an appropriate discussion or discussions to be had.	Not appropriate at initial assessment – need time to build relationship /trust.
11	Medicalised e.g. c/o dilators.	2(f) brachytherapy or caesium and they are going to be needing to use dilators you got to have that discussion pre assessment and that will be the time to discuss issues around sex & sexuality so sometimes it is putting in place it's easier in that situation than if you're having chemo its medical.	Easier to address if medicalised.
25	Treated like everyone else (LGBT patents).	2(g) shouldn't we be treating everybody the same? At the end of the day it shouldn't really matter I don't think. Unless it impacts on their life because they are having chemo. 2(h) they should be treated like everybody else. 2 (k) I think that's the same for straight people, because you can see a straight person whose dynamic is completely different. I mean, I saw a lady was 40 the other day her partner was diagnosed with cancer who was 70 & her mum had died of cancer when she was 70, so just because she was straight, she has no other family so she doesn't have the same support network either, so I don't think that your sexuality means that you have a set support groups.	Heteronormative practice.

Table (27): Extract of the process of analysis – HCP focus group: data extraction and initial coding.

Next stage involved the use of a mind map the 'list' of codes was explored to develop potential themes by clustering similar codes together to form **initial themes** and identifying the coded data which didn't fit into any of these. From this **candidate themes and sub themes** emerged. Table (28) below offers an extract from this stage of the analysis.

Description of code	Original transcript	Reflective initial comments	Emerging theme
Effects of chemotherapy.	2. Yes, particularly with chemotherapy. 1. Why relevant to chemotherapy? 2 (a)Because there is a risk when having sexual intercourse to you & your partner during the seven days of treatment so it's something which should be discussed. 2(a) chemotherapy I think holistically we might look at the relationship that they've got, the support that they have got & yes bodily fluids, chemotherapy, fertility.	Recognise the importance/ place of impact of treatment on patient's sexuality. Especially in relation to the side effects of treatment – in physical terms.	Recognise the importance of sexuality within cancer care/ impact of treatment on patient's wellbeing.
Psychological impact – body image etc.	2(b) It's the psychological effects of chemotherapy as well, the side effects effect your physical being, your body image.	Recognise the importance/ place of impact of treatment on patient's sexuality – the psychological impact.	Recognise the importance of sexuality within cancer care/ impact of treatment on patient's wellbeing.
Vaginal dryness.	2. (b) maybe vaginal dryness and basically all those things. 2(j) she said she'd mentioned vaginal dryness to the consultant in the last appointment as bothering her.	Physical impact of treatment on sexuality / reproductive tract.	Recognise the importance of sexuality within cancer care/ impact of treatment on patient's wellbeing.
Unsure when to address sexuality/sexual health in the treatment plan/journey.	2 (d) but are not sure how to be up for it and where to go to ask for information and at what point of the patients journey is it an appropriate discussion or discussions to be had.	Not appropriate at initial assessment – need time to build relationship/trust.	When to address sexuality /sexual health in the treatment plan /journey.
Medicalised e.g. c/o dilators.	2(f) brachytherapy or caesium and they are going to be needing to use dilators you got to have that discussion pre assessment and that will be the time to discuss issues around sex & sexuality so sometimes it is putting in place it's easier in that situation than if you're having chemo its medical.	Easier to address if medicalised.	Easier if medicalised.
Treated like everyone else (LGBT patients).	2(g) shouldn't we be treating everybody the same? At the end of the day it shouldn't really matter I don't think. Unless it impacts on their life because they are having chemo. 2(h) they should be treated like everybody else. 2 (k) I think that's the same for straight people, because you can see a straight person whose dynamic is completely different. I mean, I saw a lady was 40 the other day her partner was diagnosed with cancer who was 70 & her mum had died of cancer when she was 70, so just because she was straight, she has no other family so she doesn't have the same support network either, so I don't think that your sexuality means that you have a set support groups.	Heteronormative practice.	Heteronormative practice.

Table (28) - Extract of process of analysis – HCP focus group: Theme generation.

The final stage consisted of reviewing the themes by reading the extracts within each to ensure that they formed a coherent 'internal' pattern and then moving onto reviewing the themes in relation to the whole data set. Next, by going back to the collated data extracts for each theme and organising these into a coherent and internally consistent account (with accompanying text) the analysis concluded by **defining and reviewing the themes**. This safeguarded that they captured the essence of what each theme was about and identifying what aspect of the

data each theme captured, together with how these themes fitted together in the overall picture of the data.

Findings

Table (29) below identifies the seven themes generated from this stage of the analysis.

Impact on sexuality and sexual health of cancer and treatments.	Barriers to addressing issues in practice (including lack of pre- registration preparation and self-awareness).
Lack of awareness / knowledge of LGBT specific care needs leading to heteronormative practice.	Use of tools to aid assessment and management-including signposting and resources.
Medicalised and the medical model of care.	The role of the clinical nurse specialist for more complex care.
Communication skills in practice.	

Table (29): Final themes generated from the analysis: HCP focus group.

As will be seen from the following discussion, on the whole themes addressed some but not all aspects of the area of sexuality, sexual health (incorporating psychosexual health) and relationships in cancer care in general **and not only** specifically in relation to LGBT individuals.

Impact on sexuality and sexual health of cancer and treatments

Most of the participants in the focus group reported that they were aware that cancers and their treatments can impact on the patient's sexuality and sexual health. On the whole their responses were related to the effect of the different treatment regimes, especially chemotherapy, radiotherapy and brachytherapy. They did volunteer information regarding the impact of chemotherapy on patients and their partners in terms of the safety of sexual intimacy during treatment.

"Because there is a risk when having sexual intercourse to you and your partner during the seven days of treatment so it's something which should be discussed."
[HCP Fg Participant 2]

However, this fails to recognise the need the patients have for non-sexual intimacy and /or comfort during distressing treatments.

Along with this the participants identified that chemotherapy can cause alterations in regards to the woman's menopausal status, causing a premature menopause with the adjunctive

problems with vaginal dryness and issues with fertility. The second of these was seen as a particular issue for patients for whom having children was part of their life plan and seen as damaging to their sense of femininity, wholeness and sexual 'being'. It would appear that again the practitioners focused on the clinical impact on their patients' lives, whilst failing to recognise the psychological effects of loss experienced by their patients and their partners. Loss of fertility and loss of future hopes, dreams and plans. Patients describe the need to grieve for their former self and life.

"For woman it can make you feel, like not whole I mean that if this was their plan, their life plan that this was going to be their next step in their life plan. Now cancers come along and the baby is not going to happen."
[HCP Fg Participant 2(d)]

This participant went on to say:

"I think alongside that is the big issue of fertility as well. For some people if they know they can't have children, if that's what they chemo is going to do to them, they may not want to have sex."
[HCP Fg Participant 2(d)]

Some of the group did point out that for lesbian women the problem with fertility could be seen and addressed in terms of surrogacy. Initially, this was reassuring to hear as it did not echo the well - publicised experience of celebrity Sue Perkins who after admitting she was gay was told by a consultant " ...Well, that makes it easier. You're infertile. You can't have kids" (The Guardian, 2015). However, on reflection, but this was in contrast to the experiences of the women reported earlier where none of the women had reported being offered the option of egg collection and storage for surrogacy, something that it is increasingly be recognised should be offered to all women, prior to treatment such as chemotherapy.

The impact of treatments, especially chemotherapy on an individual's body image was identified as being significant and recognised by the participants. Along with the other physical effects of chemotherapy, the psychological impact on the person's body image has long been recognised within the professional literature and increasingly addressed within the patient support literature and information. However, whilst the practitioners were aware of the impact some of them felt under prepared to deal with these issues with their patients.

"It's the psychological effects of chemotherapy as well, the side effects effect your physical being, your body image. I know about this, but apart from advising about scalp cooling caps and arranging for a wig fitting I don't really feel I know what to do."
[HCP Fg Participant 2(b)]

The participants did acknowledge the impact of treatment on the individual's sense of wellbeing, and what they can expect to happen during their treatment and after its completion. Also that patients and their significant others frequently feel 'out of control' at such times, not knowing what to expect, fearful of side effects, the impact on their lives generally (including relationship, family relationships, finances) and fearful for the future. It was recognised by the participants that it was the responsibility of the health care team to assist their patients and significant others during these often difficult times. In addition, they also spoke of the importance of 'normalising' feelings and experiences for patients, again as a way of helping them feel 'in control' of their situation and not becoming anxious that they are experiencing something 'abnormal'.

"Yeah, it's like after treatment what people could expect or what would be normal to expect as normal for them, are these things normal to expect to feel this way, that's important. You don't always bring that up in the initial assessment or it could be through treatment or towards the end. There's a survivorship programme that tries to follow things up. Yeah pre and post treatment as well, you know after treatment if there are any alterations in their body or how their body functions are their emotional feelings is it normal is it going to be normal? Should I feel like this - that's important"
[HCPFg Participant 2(d)]

Interestingly, none of the participants spoke about the potentially devastating impact of surgical interventions used for the treatment of cancer. Which are known to effect both the individual's sexuality and body image. Or of the actual problems that can follow in terms of their role in supporting psychological wellbeing. They seemed unaware of their omissions, as they focussed on addressing the more obvious physiological factors

Barriers to addressing issues in practice

Having identified that the perceived impact of cancer treatments may have on patients sexuality, sexual health, relationships and wellbeing the participants demonstrated a number of barriers which they felt existed, and which prevented practitioners from addressing these in their practice.

The primary barrier was the practitioners not knowing how to address the issues with their patients. In part they felt this was due to a lack of knowledge of the impact on an individuals and couples sexuality and relationships which result from cancer and treatments. Although, as described in the previous section the practitioners were aware of the general or more common side effects of treatment especially chemotherapy and to a less extent radiotherapy, they did not feel they had sufficient knowledge of how these might impact upon the individual or couple in a more holistic way. The participants, in common with many of their fellow practitioners (Lavin & Hyde, 2006, Olsson, Berglund & Larson, 2012) appeared to view

sexuality from a very sex focussed perspective, which equated sexuality with sex /sexual function and not adopting a wider, more encompassing view. In many respects this focus on the impact on sexual function is an unrecognised barrier to working with patients and partners, sexual function was seen to be too personal and too sensitive a topic to talk about.

“...Yeah, I know how important these things are for patients, but really don’t know how to broach the subject with them. I don’t feel I have the know how to do this. It’s such a sensitive topic. Um, I guess that it’s not that I’m not willing to try, but don’t feel I know how to enough.”
[HCPFg Participant 2(h)]

This recognition of the lack of knowledge to approach sexuality in more holistic terms (encompassing relationships - including family and friend relationships, personal and partnership roles, self-image /concept, together with sexual function /expression) contributes to the practitioner’s sense of feeling under prepared to address these areas with their patients. It could be argued that by adopting a more holistic perspective the practitioners could begin to recognise that they are already assessing and addressing the patients sexuality needs simply by asking (as they do) ‘who is there for you at home? Who will be able to help to support you whilst you are having your treatment?’ Once accepted this would lead naturally and easily into discussion of more emotive issues.

Linked to the issue of perceived lack of knowledge and ‘know how’ the participants also revealed that they did not feel confident in their ability to work with their patients and partners in relation to their sexuality and relationship needs. They felt that in addition to a lack of knowledge they did not have the competence to do so, this lack of confidence and competence made them feel anxious about this element of practice.

“Um, yeah that’s right, well I personally don’t feel very confident to talk to patients about sex. What’s it got to do with their illness! It always feels a bit scary to think about doing this, it’s well outside my comfort zone”
HCPFg Participant 2(d)]

These comments have to be a cause for concern as the education and training programmes for specialist practitioners should include issues of sexuality and communication skills for professionals. However, they did point out that an element behind their lack of competence was the lack of preparation provided within their pre-registration education.

"I think when you are actually like a student nurse it's not really talked about. So when you actually go out as a nurse you just expected to learn from experience really, so maybe when you're a student it should be spoken about more.... The only thing that we had similar one lecture about HIV/AIDS which isn't really related to sexuality it's a disease just like any other disease isn't it, but didn't really have anything more about that.....In terms of the sensitivity of these elements of their patients' lives, some of the practitioners queried whether it was an appropriate area for nurses to assessing and addressing. They also identified that it was a very individual thing for patients, some feeling more comfortable to be asked, whilst others were not."
[HCPFg Participant 2(L)]

Thus, reflecting the findings of the exploration of the undergraduate nursing curriculum in regards to sexuality and sexual health (see Chapter Five) the participants identified a lack within their pre - registration education of coverage of these topics. This in turn made them feel unprepared to address these areas in their post qualifying practice. It has to be accepted that, it is not inconceivable that for these practitioners, although they had increased knowledge and understanding of the theoretical and clinical aspects of care, the specialist programmes had not been sufficient to enable them to progress from little knowledge to confident practitioner.

There also appeared to be a gender issue - presenting a barrier.

"... feel uncomfortable as a younger male. I may skim over issues. Maybe my confidence and lack of knowledge."
HCPFg Participant 2(f)]

Unfortunately, this lack of knowledge and awareness was also the case when looking at the needs of individuals from the LGBT community. Where this was addressed within their pre - registration education it was only seen in terms of STI /HIV not the wider context of LGBT lives and health. It is hardly surprising that the practitioners felt under confident or competent in these areas of practice. Furthermore, this recognition of the absence within their pre-registration education of providing appropriate care may have led to a failure to acknowledge and address the specific needs of people from this community. Contributing to the heteronormative practice to be discussed later in this chapter. Whilst it was honest of the practitioners to admit their lack of knowledge and competence, demonstrating their acceptance and trust of the interviewer, it does not solve the problem. In terms of the sensitivity of these elements of their patients' lives, some of the practitioners even queried whether it was an appropriate area for nurses to assessing and addressing.

“yeah, it’s a sensitive subject that a lot of people say, I think some people don’t mind talking about their bowels or urine but I then I think when it comes to sex it’s not only embarrassment for me but embarrassment for the patients”
[HCPFg Participant 2(i)]

They believed that sexuality was a very individual thing for patients, some reporting feeling more comfortable to be asked, whilst others were not.

“Sometimes I think it depends on how open the patient is cause if the patient are open and willing to speak then it’s easier than if you broach the subject and they just shut down and you can see they are uncomfortable you know, cause their just like oh they just think like...”
[HCPFg Participant 2(h)]

These quotes from the participants demonstrated both their own reluctance to broach the subject. It was interesting that their nurse education and training had led to them overcoming and treating as normal issues such as urinary and faecal continence and incontinence, which are taboo for many patients, they had not overcome the barrier of discussing intimacy and sexuality. Whilst identifying that it could be an embarrassing area for patients to discuss, the practitioners nevertheless expected that if patients and partners experienced difficulties they would be likely to raise the issue with the practitioners. This, however fails to acknowledge, that unless the health care practitioner ‘gives permission’ for the patient to discuss their worries, for example by including it as a routine part of both the initial and ongoing assessment, the patient or partner may at best believe that their worries are not a legitimate part of their care or worse still, that they are somehow abnormal wanting to discuss such matters at time of a life threatening illness. In addition, these practitioners identified a range of levels of willingness of qualified practitioners to assess and address sexuality and sexual health with their patients.

Another barrier identified by some of the participants was the need for a degree of self - confidence and comfort in dealing with the sexuality side of patient care. Perhaps due to greater maturity, but also linked to the person’s upbringing, especially in terms of their religious background, for some this subject just could not be raised. Some staff displayed great discomfort when talking about sexual issues or in some cases simply hearing about them from other staff:

"I think it very much depends on, I think patients get a bit of pot luck with their nurse because I was talking to my colleagues about this study and then I mentioned it to a nurse who from India and very Catholic and she looked like absolutely horrified at the conversation where as another nurse whose my sort of age we were just chatting about it quite openly and freely. So I think it's really it just depends on what nurse the patient knows and sees ,especially as a senior nurse as your worker as is the case on an oncology unit you might see different nurses every time, but if that's the nurse you're, stuck with, you have you might never want to bring that up and cause initial embarrassment"
[HCPFg Participant 2(d)]

As identified by the above practitioner, the experience of the patient is very reliant on the allocation of the nurse/s on the day unit and caseload, or as she called it '*pot luck*'. It was seen as important that nurses who do not feel comfortable with their patient's sexuality, psychosexual health and relationships should feel able to refer the patient to a staff member more able to manage their needs. There is a need to develop the nurse's self - awareness to help them recognise that these are areas may be too difficult for them to work with. And in some cases they need to have the skills for professional referral without making the patient and /or partner feel disrespected, difficult or somehow abnormal. In addition some participants questioned whether patients actually want these areas of their lives addressed by their health care team.

"I was just wondering, you know we know that professionally we don't address it well, but is there anything there from patients that actually say 'yes this was not addressed' or is it just them thinking..?"
[HCPFg Participant 2(l)]

The practitioners also admitted that they feared that they may '*open a can of worms*' that they did not know how to manage. This being the case where the patient was experiencing sexual problems which were outside of the practitioners experience and where a referral would be an appropriate course of action. The practitioners also said that they do not have sufficient information about either internal support or external organisations (both local and national) to whom the patient could be signposted or referred to. This situation is reminiscent of the worries practitioners have expressed in regards to domestic abuse, where they were unwilling to ask 'THE' question for fear of finding out that the patient was in an abusive situation and /or the situation raised safeguarding issues (Bacchus & Mezey et al , 2002, Wathen & Jamieson et al, 2008). Fortunately, with appropriate training and education many practitioners feel confident and competent to deal with this situation and are now able to provide more comprehensive and empowering interventions for the patients /individuals concerned. Similar strategies and guidelines need to be developed in the areas of sexuality, sexual health and relationships in cancer care.

Another expressed barrier, was that some participants were unsure when within the patients treatment 'journey' it would be the most appropriate to broach the subject, should it be at the beginning prior to treatment, during ongoing treatment, or towards completion. Doubts about whether patients need to know the potential sexual side effects of treatment were raised, as patients and the partners have so much information to process, especially at the beginning of treatment it could be inappropriate to add more for them to consider.

"but are not sure how to be up for it and where to go to ask for information and at what point of the patients journey is it an appropriate discussion or discussions to be had"

[HCPFg Participant 2(d)]

"I think in our booklet there is a section, but I've never looked at it"

[HCPFg Participant 2(l)]

Not all of the participants were aware of the patient information booklets or professional websites available, which amongst other things include sections (or in some cases whole booklets) on the impact of cancer and treatments on an individuals and couples sexuality.

Two more issues, lack of time and a lack of privacy were identified as logistical barriers experienced by the practitioners. The lack of time was seen as a particular problem at the pre-treatment appointment when there is so much for the practitioner to discuss with the patient and partner. The impact on their sexuality was seen as low on the priority list, it was something however, which could be briefly mentioned as it then leaves 'the door open' for further discussion later in the treatment journey.

"When we say have a new patient chat with a patient you've got to do a number of things and you're over scheduled in time and you've got patients queuing outside for their chat as well. And there are key points on the holistic assessment which you know you have got to talk about basic emergencies, treatment side effects of chemo."

[HCPFg Participant 2(a)]

A lack of privacy was seen to be a particular issue during chemotherapy as the outpatient units are extremely busy, with numerous patients and little room for private discussion.

"...to talk to you about something I don't know where, because the next time you see them they are having chemo in the middle of a day case unit with 30 people so it's hard"

[HCPFg Participant 2(a)]

As a result of these logistical barriers, what were viewed as the longer term problems and consequences were only addressed, if at all during the survivorship programme, where one exists. They may be picked up by post treatment support groups, either run by the cancer services or by external organisations such as Breast Cancer Care or Jo's Cervical Cancer Trust. However, in terms of their needs, as previously discussed (page 106) these groups

were found by the women in this study to be very heterosexually focussed and not to meet the specific needs of the lesbian women. Furthermore, by the time the women and their partners reached the end of their hospital focussed treatment and care they may already have experienced difficulties with their intimate relationship which could have been prevented with minimal 'permission giving' and focussed /cancer specific information from staff much earlier in their treatment journey. Thereby, reducing unnecessary distress for the patient and their partner.

Model of care.

The participants suggested that it is easier to talk to patients about the impact on their sexuality and particularly sexual functioning of their cancer treatment where there was a clear and obvious impact. Such a case was identified when patients are being prepared for brachytherapy for cervical cancer. In this situation the patients need to be educated about the reasons for the use of vaginal trainers post treatment, together with the techniques involved in their insertion and the importance of using vaginal dilators post treatment in order to maintain a patent vagina. Without the use of the dilators the women will find penetrative sex (of whatever type) very painful, if not impossible. The participants recognised this need and appeared quite comfortable talking to their patients about the use of the vaginal dilators.

“brachytherapy or caesium and they are going to be needing to use dilators you got to have that discussion pre assessment and that will be the time to discuss issues around sex and sexuality so sometimes it is putting in place it's easier in that situation than if you're having chemo its medical..”

[HCPFg Participant 2(f)]

This was in contrast to others in the group who overall, felt under prepared, but were willing to broach the subject and answer patient questions (if they could) about the effects on their physical sexuality, but psychosexual health and relationships of their cancer and treatments were seen differently. Although they recognised the patients' needs and sometimes distress in these areas, the extent to which they felt able to address these was limited. They had tried to respond to the psychological 'suffering' their patients displayed, but reported that at times they did not find the same to be true of their medical colleagues, who they reported did not see these areas as being a priority for patients - stating that their role was to save the patient's life rather than being so concerned about the quality of life afterwards. This showed the differences in the models of care /practice between the two professions.

"I had a lady, spoke to a lady once and it's the only time it's ever been brought up and she came to the day unit for treatment and she said she'd mentioned vaginal dryness to the consultant in the last appointment as bothering her and she said that she felt that it was just way on the bottom of his list of priorities and she was with her husband and i felt, it was a shock to me that she asked me, but obviously she could open up to me even in front of her husband she said, oh I've got this sensitive question to ask you and I thought you might be able to answer and I said well obviously what did the consultant say that you didn't like the sound of, and she said oh he just brushed it off as if there like things you can buy over the counter for that and you know and that's the least of your worries"
[HCPFg Participant 2(j)]

This practitioner had clearly been willing to listen and answer whatever the patient asked and was concerned about the medical response. However, while it was positive to hear that patients felt able to ask the nurse intimate questions, but it was disappointing that it had been a shock for the nurse. The result of this combination of medicine and limited nursing responses is that the patient may still not have been given a fully supportive answer to her question, and this might well affect her willingness to ask about such personal issues in the future.

Communication skills in practice

Although the participants felt they lacked the knowledge and confidence to assess and address their patients' needs in regards to their sexuality and psychosexual health it was clear that they already possessed some of the communication skills do to so effectively. In addition, as alluded to previously it appeared to be the perceived sensitivity for the patients of the sexual subjects and questions which made the practitioners feel embarrassed and uncomfortable. Some of the participants were however, already talking to their patients about the wider perspectives of sexuality but failed to recognise that this was what they are doing.

"I think it's important to introduce yourself to the family as well, as they are there as support so when you do a new patient chat they are usually the ones that are there listening, they are there to take in the information, that's the only time that I'd bring it up - but that's not bringing up sexuality that's just bringing up who have you brought with you today."
[HCPFg Participant 2(c)]

As good communication skills are at the heart of the practitioner - patient relationship, there is a clear need to both empower practitioners to recognise and value /validate their existing communication skills, together with extending their practice with the use of more advanced communication skills. This includes the skills of asking difficult questions and dealing with sensitive subjects. As previously discussed some practitioners would find it very difficult to utilise more advanced communication skills with patients in this area, and would need to feel confident to professionally refer the patients to another more appropriate member of the care team.

Use of tools to aid assessment and management (including signposting and resources)

When looking at what would pragmatically aid the participants explore the sexuality, psychosexual health and relationship issues with their patients, several strategies were identified which link to the above theme. Development of illness specific frequently asked questions regarding the known impact of the cancer and the specific treatments on individual sexuality, psychosexual health and relationships. These could be given to patients, with the practitioner stating that if the patient has any queries about any areas they are free to ask about these. Thus the practitioner is paving the way for the patient and /or partner to express any concerns, whilst at the same time 'normalising' their experiences together. In addition the information may be sufficient for the patients and /or partners so they are do not feel the need to ask any questions. Thereby, the practitioner has addressed the unexpressed need, lessening their anxieties about the subjects and their perceived lack of knowledge and skills in this area. In addition, the practitioner could also use the information to guide their discussions with the patients and /or partners, almost as an aide de memoire, this is seen as particularly useful for 'novice' practitioners.

"A frequently asked questions you could have may be similar to a list of things that are being highlighted you then have a guide to go to those sooner than the rarer things that someone might bring up..."

[HCPFg Participant 2(c)]

Existing questionnaires were also identified as useful, both in terms of providing a 'take home' form to complete, which could be brought back to the next appointment and followed up with a discussion with a practitioner on areas the patient identifies as being of concern. The use of questionnaires in this way would enable the patients sexuality, psychosexual health and relationships to be recognised as legitimate areas for discussion with health care professionals, whilst also offering the patient the possibility of 'closing the door' on any exploration or discussion.

The practitioner's felt that the patients would feel more comfortable with this approach, than with direct questioning. In addition, the use of the frequently asked questions and questionnaire could be put to one side by the patient and /or partner until they chose to emotionally to engage with it. Patients often say that the sexual and intimate side of their relationship is the last thing on their mind when they are receiving active treatment for their cancer, something reported by some of the women in this study (see pages 97 - 100).

“maybe a questionnaire that you can say to them, look go home and read this and you can fill it out if you want to; is there anything there you feel we need to address. Then maybe then they would come up with things that may be they wouldn't think at first that they could address with you, so are you worried about you know things that happen during sex life and this that and the other and then they would come back and say whatever or just not bring it back at all. I think most people would feel comfortable with something like that”

[HCPFg Participant 2(c)]

Some of the participants pointed out that the use of quality of life questionnaires such as the Health Related Quality of Life Questionnaire (HRQLQ) (CDC, 2010) are used in the care and management of their cancer patients. These questionnaires have been shown to foster patient - health care practitioner communication, help identify overlooked problems, together with evaluating the impact of treatment on individuals, furthermore these questionnaires have a section related directly to sexual functioning. They therefore offer the practitioners the opportunity to open up the discussion of these issues with patients as a matter of routine. However, as identified by the participant below, this ‘follow up’ questioning and exploration is still very practitioner dependent.

“A lot of, um, a lot of places I work on do like quality of life questionnaires and as part of that they do ask like ‘in the past month or so, how interested have you been in sex? Or then you’ve always got the opportunity then to address it but then going back to its pot luck which nurse you have its whether that nurse will look and think, oh I’d better talk about or actually no I don’t actually want to talk about it.”

[HCPFg Participant 2(e)]

The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaires, which are frequently used within a research setting the EORTC - QLQ have specific ‘modules’ related to body image, sexual functioning and sexual enjoyment. Some of these questionnaires have been extended to cover specific types of cancer for example breast cancer (EORTC QLQ - B23), ovarian cancer (EURTC QLQ - OV28) and colorectal cancer (EORTC QLQ - CR 38). It is suggested that the use of modified versions of these within a non-research clinical setting could be useful, again ‘normalising’ the potential issues, offering patients the opportunity to either discuss their concerns or chose not to. However, no matter how appropriate or useful all these questionnaires are for equity in care all nurses need not only to use them but also to follow up on responses. The ‘pot luck’ element is not acceptable.

The lack of up to date resources related to the subjects, together with lack of knowledge and awareness of access to appropriate information, agencies and organisations (for both

heterosexual and LGBT patients) was also identified as barriers to addressing the subjects with patients. The participants felt that specific information relevant to the type of cancer, treatment and stage of the patients 'cancer journey' should be available to them in their clinical settings and suggested that these need to be collated, updated and possibly available on a UK cancer organisation website for example Macmillan Cancer Support. This would maximise accuracy and currency of information. However, information about local support services would also be needed, as national websites would not necessarily have the local information needed.

*"I think that unless it's collated you don't, and 'cause it's not something we'd use day to day unless it's down in one pack."
 "Is there anything on the Macmillan website something like that. Related to specifics or information there?"
 "something like that. Then you'd know it was updated, cause everywhere things like leaflets get lost and when it's not something that's not used a lot it is especially going lost or .."*

[HCPFg Participants2 (e & f)]

It was disappointing to hear that experienced practitioners did not feel able to locate the specific information themselves instead they appeared to need 'spoon feeding'.

Lack of awareness/knowledge of LGBT specific care needs and heteronormative practice

When exploring with the participants their degree of 'preparedness' to address the sexuality, psychosexual health relationship issues arising from cancer and treatments with patients and /or partners from the LGBT community, the practitioners identified several areas needed further exploration. Firstly, the participants questioned whether it was necessary to have knowledge of a patients sexual orientation, was it even relevant to their treatment and care?

"The question may be should we be asking them? Should we? Is it relevant, not relevant but do we want to put everyone in a box, should we be asking at all, shouldn't we be treating everybody the same?"

[HCPFg Participants2(g)]

Currently sexual orientation monitoring does not take place in the UK, despite lobbying work from within the LGBT community to do so (Baldwin, 2012, Hunt & Cowan, 2015). It is therefore impossible to undertake meaningful health surveillance or check for any evidence based links between LGBT /sexual minority status and the incidence and prevalence of ill health, including cancer. Currently, as could be seen from the literature review there appears to be contradictory evidence available to both public health and health practitioners in this area. The evidence

available does indicate that there are some lifestyle and health behaviour factors e.g. lack of uptake of cervical and breast screening from the lesbian community which put them at greater risk of late detection of cervical and breast cancer (Quinn & Schabath et al, 2015). It would appear, therefore that, from a public health and disease prevention perspective it is important for health care professionals to ask about and be aware of their patient's sexual orientation. Health promotion is an integral part of health care professional's roles and has been shown to lead to improved health outcomes including adherence to treatment, quality of life, increased knowledge of patients of their illness and improved self - management (Bosch - Capblanc et al, 2009, Keleher et al, 2009, Kemppainen, Tossavainen & Turunen, 2012). It is suggested therefore, that in order for practitioners to competently fulfil this role with patients from the LGBT community they need to know who their patients are in terms of sexual orientation, together with possessing an awareness of what this means in terms of the LGBT specific health needs.

Possibly due to the positive changes in legislation and societal attitudes towards same sex relationships over the past couple of decades in the UK many of the nurses in the focus group felt that there was no need to know about a patient's sexual orientation as they would treat every patient the same regardless of sexual orientation. However, this was not the view of some of the lesbian women interviewed in this study.

***"Shouldn't we be treating everybody the same? At the end of the day it shouldn't really matter I don't think. Unless it impacts on their life because they are having chemo."
"they should be treated like everybody else."***

[HCPFg Participant 2(g)]

Whilst on the one hand it was refreshing to hear that these practitioners were not displaying negative or homophobic attitudes towards the patients in their care, it also displays heteronormative practice. By adopting the 'all patients are the same' attitude which Goldberg et al (2011) referred to as "care practices blind to difference", the participants were failing to recognise both the unique and individual nature of **all** patients and the specific healthcare needs and anxieties that individuals from the LGBT community might experience. Furthermore, they failed to recognise how social factors - such as heteronormativity shape both the patients and nurses life experiences, health, and health - care interactions. Mathieson's (1998) study suggested that in order to provide LGB culturally sensitive care practitioners need to be able to grasp what it means to patients to be LGB and how societal attitudes and responses to sexual orientation can affect health and health care. Post legislation and societal changes it is suggested that this should be extended to include an understanding

of what it means to be LGB in a generational sense. Many older lesbians and gay men have very different and negative experiences of what it meant to be homosexual before homosexuality was decriminalised, de-pathologised and their relationships were given equal status with those of heterosexual people. Lesbians and gay men of these generations have very different life experiences than their current, younger counterparts. Many older LGB individuals have lived through the 'time of AIDS' and experienced openly homophobic healthcare staff, some will have witnessed or been treated with 'conversion therapy', thus making them hesitant to either seek health care or to be 'out' with healthcare staff. (Stonewall, 2015).

Linked to the above was the participant's fear of offending their patients through the use of perceived inappropriate language or behaviour. This very much reflects the issues previously identified and discussed by Rödahl (2009) and Goldberg et al (2011) who suggested that the reality of LGBT disrupts the practitioners everyday assumptions (of heterosexual normality) leaving them feeling uncomfortable. Additionally, the patients in these studies reported that their sexual orientation appeared to make the health care staff feel unconfident, embarrassed and anxious about saying or doing something which could be seen by patients as inappropriate or prejudiced. The participants in this study feared offending through ignorance of LGBT issues, lifestyles and relationships, regardless of whether they held either positive or neutral attitudes towards individuals from the LGBT community, this despite good intentions can lead to 'paralysis of interactions'.

"What their problems are, what really happens, the dynamics in same sex relationships can be very, very different to heterosexual relationships, so what they experience and the types of things that we should be looking out for. So, then if somebody does get a diagnosis that can alter their relationship as it stands but also we don't know the path of their relationship so sort of, I suppose for me it would be having that sort of knowledge and kind of asking the right questions if the need arises."

[HCPFg Participant 2(c)]

"I don't see have a problem with gays and whatever, not my bag, but I don't mind how people live. I do sometimes worry that I might say the wrong thing and that they might see this in the wrong way..."

[HCPFg Participant 2 (e)]

"I never assume because, it may not be right, ... because I've put myself in the ... so many times saying oh is this your dad no it's my husband, or is this your husband no it's my brother ,like so, this your friend no it's my girlfriend, so then you know , what's going on"

[HCPFg Participant 2(k)]

There appeared to be a genuine desire on the part of some of the participants to have a better understanding of LGBT relationship dynamics, seeing this as an important part of the nurse – patient relationship. This being the case particularly where that relationship would be sustained over a long period of time.

"I suppose being informed of the things these groups encounter..... and what happens is that for us we see patients very sporadically over a very long time so we get to build a rapport with them, we get to know them on a different level and some of them become almost a bit like one of your family because you're seeing them all the time so because of that we are, they are a bit more privy to what your life is and we become more privy to their life is, so it would just be it suppose for me to know about these issues rather than just think, oh god I don't know how to handle this or um."

[HCPFg Participants 2(c)]

The participants felt that they were unclear to where they could signpost patients for more LGBT specific or focussed help and or support. The participant were unclear whether such organisations existed and if they did where they would find them. They also questioned how well prepared these organisations were to deal with a person and /or partner effected by cancer.

"You know just know about the different services and different support groups are available."

[HCPFg Participants 2(c)]

"I think as well a list of resources for us and the patient, so they do feel comfortable completely opening up to you because actually you know may be contact these people they could help you better because they would be more expert knowledgeable in that area."

[HCPFg Participants 2(g)]

These themes reveal that there is a clear need for the availability of signposting information and resources for practitioners, both generally and LGBT specific. Together with liaison with the staff within the LGBT organisations to find out more about the services they offer, assess their 'preparedness' to work with patients with cancer and also to establish working links with particular staff - so that they feel confident about to whom they are signposting patients to. Furthermore, such liaison provides the opportunity for the LGBT specific organisations and groups to 'get to know' the staff within statutory services, thereby fostering closer, more integrated working and lessening misconceptions between the two sections of society. This would also hopefully decrease the mistrust of health care staff, which may be felt by staff within the LGBT organisations.

Role of the Clinical Nurse Specialist.

Several of the participants suggested that the clinical nurse specialists in cancer care might be best placed to discuss any sexuality, psychosexual health and /or relationship issues with patients and partners - both heterosexual and LGBT. One of the main reasons identified was the nature of the relationship that these practitioners have with patients and significant others, over an extended period of time, that is throughout their cancer 'journey'.

“... it’s like when someone says their relationship is a problem more than sexuality then you can talk about that or I guess as a CNS we get to know patients probably quite more in depth than, we know their family structures and things you can get to know people, I always try to ask oh how’s whoever husband or whoever and then you can tell really, you can gauge people and um, if it’s something they want to talk out then go ahead, if not ...”

[HCPFg Participants 2(a)]

Coupled with this is the sense from the less experienced nurses that they can rely on the clinical nurse specialist to ‘pick up’ the more complex issues or to refer the patients on to.

“There’s usually a CNS that may be involved in the patients you know after diagnosis so they have got time to spend with someone who has the expertise in general in picking up more sensitive conversations so we’ve got those to turn to but its whether they are trained to deal with this sensitive situations you know..”

[HCPFg Participants 2(g)]

It appears that there may be different ‘levels’ of practice’ - related to the nursing hierarchy, with more experienced and educated nurses taking on the more specialist and complex care. The specialist nurses being equipped with more advanced communication skills for dealing with more sensitive subjects. However, as identified in the quote above, it is questionable whether these advanced communication skills extend to addressing the patient’s sexuality, sexual health (incorporating psychosexual health) and /or relationship issues. In addition, as has already been identified, the degree of practitioner self - awareness in relation to sexuality is central to whether they are able to incorporate these aspects of care into their practice. The previous issue of ‘pot luck’ allocation of specialist practitioner to patient appears to be highly relevant in this respect. In addition, the lack of awareness and confidence when working with LGBT patients and partners identified above appears to come into play here too. If the clinical nurse specialist feels anxious and fearful of ‘getting it wrong’ with their LGBT patients, this will inhibit the development of the nurse - patient relationship. This in turn, may lead the patients to hesitate about discussing any concerns they may have their intimate and general relationship/s.

Discussion And Summarising Of The Findings From This Phase Of The Journey With Implications For Practice And Education

In Chapter Three ‘the starting point’ of the study extensive literature was reviewed regarding the health care practitioners readiness to address the impact of cancer and treatments on the sexuality, sexual health and relationships of individuals who experience of it. Together with

their practice in regards to LGBT patients in their care. In discussing the findings from the exploration with the cancer care specialist nurses focus group, areas of convergence with and divergence from the previous literature and implications for practice were identified.

Convergent findings and implications for practice and education

As with previous studies (Greener & Reagan, 1986, Girts, 1990, Saunamaki, Andersson & Engstrom, 2010, Zeng, Liu & Loke, 2011, De Vocht, 2011, Olsson et al, 2012), the practitioners in this study, whilst recognising the impact of cancer and treatments on individuals sexuality, sexual health and relationships, felt that they had an inadequate knowledge of the specific effects to address these areas with their patients. In addition, reflecting previous studies this was coupled with the practitioners also identifying barriers that prevented them from incorporating these aspects of life into their practice. Firstly, was the degree of practitioner comfort /discomfort, lack of confidence, competence and perceived lack of appropriate skills, including communication skills, especially advanced communication skill for talking with their patients about these areas (Lavin & Hyde, 2006, Beck & Justham, 2009, Olsson & Berglund, 2012). Furthermore, they identified a lack of time and privacy available for such discussions (Saunamaki, Andersson & Engstrom, 2010, Zeng, Liu & Loke, 2011). Additionally, the practitioners identified that their lack of self - awareness, including the impact of their upbringing, beliefs, attitudes and prejudices and comfort in regards to their own sexuality presented a barrier to them working effectively with their patients, reflecting both early studies (Webb, 1987, 1988, Thomas, 1990) and unfortunately more recent studies by Saunamaki, Andersson & Engstrom (2010) Zeng,Liu & Loke (2011) and Olsson et al (2012). It is sad to see how little has changed in this respect in the past 30 years, despite the changes in society that have occurred in the intervening years. This clearly represents a challenge to both healthcare practice and practice education. It is further argued that these barriers to effective working with patients in the regards to their sexuality, sexual health and relationships lead to 'professional anxiety' and avoidance in relation to this area of practice.

In terms of their practice with LGBT patients the practitioners suggested that they were worried of offending their patients through inadvertent use of non-sensitive language and actions, leading to heteronormative practice (Rondhal, 2011, Goldberg et al, 2011, Steppe, 2013). This concern with offending could also add to the 'professional anxiety' felt by health care professionals working with individuals from the LGBT communities. One of the reasons identified by the practitioners for their lack of confidence and competence in this area of practice was the lack of inclusion of sexuality and LGBT health within both their pre and post registration education. This lack of preparation reflects both previous studies and the findings

from the expert panel focus group (Lavin & Hyde, 2006, De Hart, 2008, Rondahl, 2008). It is argued that this is a further area for practice education and practice.

Divergent findings and implications for practice and education

Whilst the practitioners recognised the physical impact of cancer and treatments on individual's sexuality, sexual health and relationships, they did so by adopting a medical model of practice. Feeling quite 'safe' and 'confident' when talking to patients about the mechanical, physical effects and interventions utilised e.g. the use of vaginal dilators post cervical radiotherapy. However, some reported that they did not explain the physiological need for their use leading women to decide whether or not to use them. They also failed to explore the holistic effects of diagnosis, treatment and its outcomes on individuals, this included failing to recognise or identify the psychological impact caused by both cancer and treatments. This reflected the findings earlier in this study from the expert panel, and clearly presents a challenge to professional cancer education and practice, especially with regard to nursing practice, as this is predicated upon the concept of care rather than cure.

For the women and their partners in this study this lack of psychological support left them in limbo, seeking for support that wasn't there. The practitioners recognised this but felt that they did not possess the skills to address the psychological distress (including feeling that their lives were out of control) exhibited by their patients. Their solution prior to this study had been to focus on physical issues and not follow up the more emotive and sensitive issues. Unfortunately, this lack of psychological care reflects the experiences described by the women in this study who openly stated that the staff lacked 'the human touch'. There appears to be a clear need to develop strategies for the nursing practitioners to learn to be able to provide holistic care for their patients and significant others.

In terms of their comfort and appropriateness of addressing sexuality, sexual health and relationships with their patients the practitioners did not recognise that they had existing transferable skills which could be used when talking to patients about any issues being experienced in these areas. Sexuality and intimacy sat in separate boxes, and sadly, some of the practitioners identified that for them broaching the subject was worrying, and that they feared 'opening a can of worms'. Unfortunately it appeared that this meant these practitioners would be unlikely to identify or recognise when a patient needed help or referral on to a more skilled practitioner.

Surprisingly, in view of the amount of research and literature available to them, the practitioners identified that they felt unprepared and lacking confidence when needing to address body image issues with their patients. Given that all of the mainstay treatments for

cancer effect an individual's body image and that cancer specialist nurses work with patients effected on a daily basis this was particularly worrying. Furthermore, that they did not access the wealth of literature and information available to help guide practitioners to support and aid their patient's adaption to an altered body image (Price, 1990, Price, 2016) has to be a cause for concern. In the light of the NMC code (NMC, 2015) of conduct and the need to update and upskills that is inherent within the code this unexpected finding again presents a challenge for both pre and post registration nursing education. There is a need to include body image, the impact on body image from ill health and medical treatments, together with appropriate interventions to aid adaptation to an altered body image (both the short and longer term), within pre and post registration programmes. There also has to be emphasis on the role of lifelong learning and the responsibility that comes with professional registration, particularly when entering into a specialist role.

The practitioners did demonstrate keenness to learn and know more about LGBT relationships and lifestyles. They reported that they felt that they didn't know enough in these areas to be able to foster a good nurse - patient relationship. This reinforces the need for education and training to be provided to develop practitioner's knowledge and understanding in these areas. They identified that they would welcome specific information about LGBT specific 'help' groups, organisations and LGBT friendly practitioners to whom they could make appropriate referral or signpost their patients, is a start on the road to adequate care and support for this group.

Although some of the practitioners were keen to learn more about the experiences of people from the LGBT communities, some questioned whether it was necessary to ask about sexual orientation at all. However, as was previously identified with the expert panel the failure to recognise the differences in lived experience of people from the LGBT communities does not facilitate tailor made individual care and can lead to heteronormative practice. Nor does it recognise the potential impact on lesbian women of living as part of a minority group in a predominately heterosexual society. Working from a heteronormative model the participants were unable to report or discuss how this impacts on their fulfilling their public health /health education role with their patients who are lesbian women.

The practitioners did identify that the role of the clinical nurse specialist in addressing the sexuality, sexual health and relationship needs of the patients was crucial in complex cases. However, as most of them were clinical nurse specialists and clearly stated that they felt their own knowledge and skills in this area could be improved, especially in regards to advanced communication skills and LGBT specifics. It has to be argued that there is a clear need to provide appropriate education and training for this level of practitioner. As patients come into

to more regular contact with non - clinical nurse specialists within an oncology setting e.g. when attending for chemotherapy, other 'levels' of staff need to be provided with an appropriate depth of education and training in this area, but this was not mentioned at all.

In terms of useful tools to aid the assessment and care of patients the practitioners made several suggestions which could be incorporated into an educational toolkit and online resources. These included the use of frequently asked questions leaflet and the use of existing questionnaires (which could be completed at home). The use of a collated, and up to date resource 'pack' perhaps 'housed' by a recognised national cancer organisation such as Macmillan Cancer Support was also made. This would facilitate a process through which practitioners could have quick access, which they saw as important due to the time constraints in which they work.

Reflections On Cancer Specialist Nurses Focus Group: Implications For Practice And Education

The findings from the focus group very much mirrored those found previously with the expert panel, with the same practice implications, there were however, some differences. Firstly, the failure of the practitioners to recognise that they had existing transferrable skills which could be drawn upon in the current practice. These skills could also form the building blocks for education or training interventions /programmes, moving from the known to the unknown, showing the importance of utilising an androgogical approach to adult learning. Furthermore, it is suggested here that the practitioners might benefit from adopting a more reflective approach to their practice, in line with the NMC (2013) code. Secondly, there is a clear need to incorporate altered body image interventions into pre and post registration curricula. The recognition of the need to include both more information regarding LGBT relationships, lifestyles and health related issues and advanced communication skills within educational programmes for clinical nurse specialists. Finally, there were suggestions for the possible content of a 'toolkit' or educational package to address the current perceived shortfalls in this area of practice.

Extract from reflective journal and reflexive comments:

"It was rather heartening to hear that many of the practitioners recognised the need to try to address the sexuality, sexual health and relationship concerns of their patients, and in some instances the impact of cervical radiotherapy and prior to chemotherapy. They are beginning to recognise the need for formalised clinical practice /protocols that can be easily used. I was also heartened that the group did not demonstrate any openly homophobic responses – indeed they were, on the whole interested in how they could engage better with LGBT patients. It was disappointing – but not totally unexpected after the expert panel and

documentary analysis, that they didn't feel they possessed the necessary skills to work with their patients in this area. But at least they recognised the importance of doing so - unlike some of the previous literature."

Reflexive comments:

- Checked potential influence of own past experiences in regards to focus group plan and schedule with my supervisors prior to ethics application and running the focus group.
- Scrutiny and justification by /with the ethics committee.
- Revisited insisting literature - both sexuality in healthcare in general and cancer specific, to both inform the focus group schedule and also returned to during the analysis of the focus group transcripts.
- During the analysis of the transcripts adopted the phenomenological principles to try to ensure the voices of the participants were heard and represented.
(Including 'outlying' experiences). As a lesbian I had to be careful not to try to speak for the research participants who are on the whole, heterosexual.
- Felt like an 'outsider' with the focus group participants, possibly as a result of being a gay woman with a group of mainly heterosexual women (plus one self-identified gay man). I have often found in the past that heterosexual women are more comfortable being around gay men than they are with lesbians.

Reflecting on this I had to consider whether I may have underestimated the impact of my non - researcher identity - which may have been perceived as 'threatening' by the participants.

Chapter Eight: Journey Phase Three (C) - Revisiting the expert panel – Delphi round four

Positionality: Revisiting the facilitator role.

From my experiences with the earlier expert panel workshop I was aware that I was rather anxious about re-engaging with the group. I was very aware of my 'outsider' status and the degree of discomfort with the subject - sexuality and relationships generally, and more specifically with regards to LGBT issues which the expert panel had demonstrated previously. I needed to facilitate the group well, in order to maximise their expert knowledge and experiences. In order to do so I had to set aside my anxieties (and upset from the previous expert panel experiences) and focus on designing the workshop based on the findings from the study to date.

In keeping with the modified Delphi method the expert panel were revisited at this point in the research journey to discuss and seek confirmation and further clarification of the findings from the original workshop and questionnaire. As with the phase one expert panel the workshop was structured into two parts. It took place at a conference organised by the same international cancer educator's organisation as the previous workshop, this time in the UK, and was attended by 19 participants, of whom 11 had attended the first workshop in Poland. As previously the participant information and consent forms were distributed by the conference organisers at the commencement of the conference. This enabled the potential participants the opportunity make an informed choice about attending the focus group. See appendix six for workshop abstract.

Firstly, there was a reminder exercise exploring the meaning and definitions of the concepts of sexuality and sexual health. This refreshed the participant's thoughts about the nature of these and set the scene for the rest of the workshop. The workshop then moved onto the presentation of the findings from the original workshop and questionnaire. Time and opportunity were given for questions, areas for clarification and additional information to be offered by participants. The workshop then moved on to present and discuss the findings from the documentary analysis, healthcare practitioner focus group, the interviews and questionnaires with the lesbian women and their partners.

Following this the participants moved into group work with four groups, who were given a case study drawn from the interviews with the lesbian women who had experienced cancer and asked to explore the following:

1. What are Paula and Sue's (lesbian women) care needs in relation to their sexuality, sexual health and relationship? What would help you address Paula and Sue's care needs?
2. What are the implications for you as cancer educators and practitioners.
3. What would be useful for you to have in a 'toolkit' to help c/o your practice in relation to sexuality, sexual health and relationships and LGBT specifics?

The workshop ended following feedback and discussion of the group work with a brief discussion with the participants regarding the way forward with the study.

Data collection and analysis

As with the original expert panel workshop the method advocated by Lofland & Lofland (1995), I attempted to derive meaning from the workshop observation by completion of theoretical notes. This was undertaken through thinking and reflecting on the experience. Together with the completion of methodological notes - a critique on the workshop process/es. Throughout attempting to 'account' for myself through reflexivity and reflecting back to previous work on the topic. Structuring the observations in this manner allowed for ease of analysis the method of which is discussed in the next section. Furthermore, the use of my research diary proved to be an invaluable source of reflection and a 'space' to make sense of the occurrences both within the workshop and in out of workshop discussions with workshop participants. The workshop notes were subjected to content analysis (Lofland , Snow & Anderson et al, 2004) analysing each workshop activity sequentially. Interpretation of the analysis of the process filed notes was supported by the reflective notes and research journal as outlined above, to give meaning to the analysis.

Workshop observations

At the beginning of the workshop the findings and the themes generated from the previous expert panel (see page 54 and Table (30) below) were outlined, discussed and agreed upon.

Lack of knowledge of the impact on sexuality and relationships of cancer and treatments - generally and Lesbian and Bisexual Women (LBW).
Practitioners unease discussing and exploring sexuality generally and LBW.
Practitioners discomfort and lack of knowledge with regards to LBW.
Implications for practice and education.

Table (30): Original expert panel workshop themes

In spite of the non-personalised nature of the presentation and group work, it was interesting to note that those within the workshop groups who had participated in the original expert panel appeared to be just as uncomfortable discussing the issues being presented and explored as they had been previously. Indeed it was noticeable that some offered reasons for not being able to participate in the workshop, however, the absence again called into question, how comfortable these practitioners and educators would be when working with their cancer patients in the areas of sexuality, sexual health and relationships. The workshop observations demonstrated that the above themes were still present and relevant to the participants. Throughout many of the participants struggled with both the subjects i.e. sexuality and sexual health generally, in relation to their cancer patients and the more lesbian specific aspects of the workshop. Interestingly, many seemed more comfortable and confident when the workshop moved to the case study based group work, a format they had used throughout their training. The workshop produced a wealth of information pertaining to each of the areas of exploration.

Addressing the lesbian women's care needs care needs in relation to their sexuality, sexual health and relationships

Overall the workshop and group work appeared to be more positive in relation to sexual orientation than the original expert panel workshop. There were a number of additional participants who appeared more comfortable with LGBT orientation. This was a possible reflection of the impact of the work undertaken by the NHS and Stonewall resulting from the implementation of the Discrimination Act (2010). This focussed around policy changes to ensure equity in service provision, together with education and training all staff within the NHS to provide LGBT sensitive care. Those who were most uncomfortable tended to be the older non UK practitioners, reflecting the findings from the original expert panel. Among those who were more comfortable with the case study there was a tendency to talk of the need to treat all patients the same regardless of their sexual orientation. Whilst this is seen as a positive move forward from previous judgemental care, this practice is heteronormative in that it fails to recognise the individual life experiences and specific issues of the lesbian women. There were however some participants who openly stated they were really at a loss as to how to go about working with patients in this area, some of whom reported that as they had more 'technical' roles this was not relevant for them.

However, in terms of identifying what would help them address the lesbian women's care needs in relation to their sexuality, sexual health and relationship several strategies and interventions were identified. Namely possessing more knowledge and understanding of LGBT specific needs, more knowledge of LGBT relationships, and the provision and

instruction on the use of standard assessment tools available for sexuality, sexual health and relationships. They also reported needing advanced communication skills (discussing difficult subjects with patients).

The implications for participants as cancer educators and practitioners

It has to be a cause for concern that there were participants who reported being at a loss as to how to go about working with patients in relation to their sexuality, sexual health and relationship needs. Indeed, it is suggested here that it is psychologically safer for their patients if they do not attempt to work in these areas (Poorman, 1988). The lack of knowledge displayed also raises the issue raised earlier of how they facilitate the education of students and junior staff in these areas. This was recognised by a few who openly identified the need to be 'shown how' to address these areas of practice before providing education and training for their students. Perhaps one of their strongest recommendations was the need to teach advanced communication skills in both pre-qualifying and post qualifying education.

The participants identified what they believed would be useful sexuality, sexual health and LGBT specific practice and practice development content. These were divided into two distinct sections - practical and practice development content.

Practical Support strategies suggested

Standardised assessment questionnaires e.g. sexual health Inventory for men (SHIM).

(Erectile dysfunction questionnaire).

Information re: support groups, organisations and signposting information.

Leaflets and factsheets re: known impact of cancer etc on sexual function and sexuality (both general and disease specific).

Useful models, diagrams etc of reproductive systems to use with patients.

Recommendations re: – lubricants and sexual aids

Practice development and training

Information regarding LGBT lifestyles and relationships.

Advanced communication skills training.

Extract from reflective journal and reflexive comments:

"I was a little nervous about facilitating the workshop, because of my experiences with the previous expert panel workshop. Not to mention apprehensive about how they would view the findings of the analysis of the original workshop and questionnaire, hoping this wouldn't be viewed in a personally threatening or negative way - rather as it was intended, as an honest reflection. I was relieved that the workshop worked more 'smoothly' than previously and different perspectives were gained. The planned focus on the findings from all group and the documentary analysis worked well, as it took the spotlight off them, and also had demonstrated that they were not alone in having difficulty addressing sexuality, sexual health and relationships with their patients."

"The workshop was found to be a useful process in that it both confirmed the previous information and ideas from the expert panel. However, the difference was that it was extended to include some suggested ways forward for education to address the gaps in their knowledge and skills in regards to the sexuality, sexual health and relationship needs of their lesbian patients. It also confirmed the need to address these deficiencies through appropriate education, training and practice development."

Reflexive comments:

- Checked potential influence of own past, including previous expert panel workshop in regards to the workshop plan and content with my supervisors prior to running the workshop.
- Use of methodological notes offering a critique on the workshop process/es. Throughout this I attempted to 'account' for myself through reflexivity and reflecting back to previous work on the topic (as below).
- Revisited insistent literature - both sexuality in healthcare in general and cancer specific during the analysis of the workshop observations.

Having now gained the views and insights from both sides of the patient - healthcare professional 'divide' it was now time to 'pull together' all of these threads and to identify theories which could explain these experiences. To identify any gaps in the existing knowledge base and develop a conceptual framework to extend and improve practice in the areas of need.

Brief critical appraisal of key findings from the research journey.

Before moving on to the development of the conceptual framework arising from the critical appraisal of the findings to date, it was seen as appropriate to review the key findings from the analysis of the rich and in-depth data gathered from both the healthcare professionals and the women participating in the study. For the sake of clarity these will be presented together below.

Expert panel, documentary analysis and specialist cancer care nurses:

Looking back at the data gathered from this international expert panel, it had to be accepted that the findings had revealed a lack of educational preparation for their role which had resulted in a dearth of expertise. The first workshop demonstrated that the lack of preparedness had led to a range of avoidance techniques which they successfully used, in the initial session of the workshop. However, it has to be clearly stated that they shared one positive attribute. Consciously or in some instances unconsciously, they had accepted that they did have difficulties with this sensitive issue and were willing first to listen, and then as the session progressed to try to change. Indeed their request for a second session and then after that for a third, illustrate how far they had progressed along the journey to change purely as a result of taking the first step by agreeing to participate in the expert panel. Nevertheless, this does not alter the findings given below that:

- Most demonstrated limited or no knowledge of both the effects of cancer and treatments on **ALL** women's sexuality, sexual & psychosexual health and relationships. Not to mention not knowing the impact of these for lesbian and bisexual women or what LGBT sensitive care was.
- They demonstrated that on the whole they did not know to address sexuality, sexual health and relationships with ALL patients, and thus tended to avoid or minimise the subject.
- There was a lack of self-awareness, and as a result, the impact of self in patient interactions, and the influence of previous medical encounters seemed not to have been considered at all. Coupled with a lack of self - knowledge regarding their own feelings regarding sexuality and intimacy, this had led to the conscious or unconscious development of a set of avoidance strategies. One or two of the younger participants made major personal changes in both their perspective and their search for more knowledge (a result from attending the first expert panel workshop), and have become vocal champions of the need to change practice – in terms of both sexuality and the importance of effective communication skills in practice.

- To add to these general problems the experts demonstrated a lack of knowledge about and discomfort with lesbian orientation, lifestyles and relationships. They spoke clearly of their practical worries including fear they would offend, feeling that they did not know the right language to use.

From the documentary analysis it was clear that (at least in part) there was a lack of education and direction in communication in general and the issues of sexuality and intimacy in particular within pre and qualifying education. Also that where these had been included in their education the focus had actually been on their role in the fields of contraception & HIV. The result of the paucity of education in these topic areas and more advanced communication skills (e.g. having difficult or sensitive discussions) left them to feeling ill equipped and lacking in competence and confidence. The experts reported that they felt that their culture, class together with their own value system and beliefs all impacted upon the practitioner/patient relationship.

Due to all of this they reported feeling **anxiety** before consultations where sensitive or contentious issues could be raised. It was evident throughout the workshop that they did not know how to probe, sense individual feelings and respond, and as a result could not find the bridge for communication. They were afraid that the whole professional relationship would be rejected if they get the initial interaction wrong, this resulted in a tendency to avoid the topic area rather than trying. Some practitioners had resolved their fears by openly saying it was not their role (medical staff mainly). Whilst this made them feel more comfortable it meant that, for the patient it was clearly 'pot luck' whether they saw a practitioner who was willing to attempt to discuss what are essential elements of humanised care or would rationalise their reasons for avoiding the subject.

It was extremely disappointing to find that the few who stated they were willing to initiate discussions actually saw sexuality, sexual health and relationships as needing addressing where there were concerns around fertility and /or the medicalised aspects of care e.g. for women who may need to use vaginal dilators. Sadly it also emerged that for most, discussion with the patients about the rationale for their usage only focused on medical reasons for their use, and not the reality that without them women could experience problems in their everyday activities. This medicalisation made it easier for them to speak to their patients 'legitimately', but actually did not help the patients accept or understand their real role in rehabilitation. It is essential that things change and practitioners start to address both the clinical aspects of care and the **KEY psychological aspects**.

An unexpected finding their ability to articulate how they themselves felt, with the generally agreed feeling that as the professionals they felt lonely when not properly prepared and trained to address these areas in practice. They also identified that they wanted more education, training, guidelines and skills to feel both confident and competent, but prior to this workshop had accepted that this was 'just how it was' and had not tried to increase their knowledge or remedy the situation..

Overall, whilst being horrified and mortified by the response given (especially from the initial expert panel), it was clear that the practitioners had on the whole have the willingness to engage with learning 'how to' address the identified sensitive areas with patients in practice, through appropriate education and training. This workshop had been a learning experience for all concerned, for the professionals they had had to confront gaps in their knowledge and ultimately their practice. While I had to come to terms with the fact that the situation appeared not to have changed in the decade(s) I had been working in this field. I too needed to look at how to address these key issues without making value judgments, or my feelings too explicit. To develop a way to take these experts and their colleagues with me into a much more pro-active approach to the needs of their women patients.

The lesbian women:

The data sets revealed that the women had found the immensity of the impact of the cancer and its treatment unexpected. They clearly articulated unlooked for treatment issues and side effects which had impacted on their sexuality, sexual health and relationships. These included body image changes which they had not anticipated, as prior to treatment their focus had been on 'dealing with' the cancer. They had not looked beyond the diagnosis and the need for medical and surgical interventions. They identified what they referred to as the 'roller coaster ride' of cancer. This can be summarised as

- Physical impact which included
 - The effects of the menopause
 - Altered sexual feelings/arousal, including the need to alter where they needed to be touched to become aroused.
 - No interest in sex or sexual intimacy during treatment phase.
- 'New reality' – impacting on their relationships, seen as a challenge as their partner had not necessarily been seen as following the same journey.
- Fear of experiencing homophobia when interacting with healthcare professionals, including fears that partners wouldn't be included

Perhaps not surprisingly, these women talked about the overall result of their experiences leading to at times pushing their partners away from them as they were struggling to find a way to cope. The paradox that arises from this is that it led to isolation and vulnerability, at a time when they wanted and needed, closeness with, and support from their partners. They needed to re-evaluate their own role as a person and/or partner in order to be able to move forward with, rather than separately from their partner. Some of the women openly stated that they now felt unattractive and dirty, therefore questioning how could partners find them attractive and want to be intimate. The women described how this feeling left them fearing that the long term maintenance of the relationship was in jeopardy. The women went on to identify that where the couple were able to talk/ communicate with each other they had been able to develop a different but closer relationship and had ultimately fared better in regards to resuming of intimacy. However, sadly for some who had not been able to find ways to communicate it had led to distance between them and in some instances separation. Thus, for these women the outcomes of the 'roller coaster' were compounded by the loss of their partner. And in view of the psychological impact of their diagnosis and treatment and its impact on their previous relationship the women had concerns about their ability to meet new friends and form new relationships.

Overall it was evident that for the women with partners at the start of their cancer journey that had not been aware of the long term impact. However, as time progressed the immensity of the changes had become apparent. Sadly, they had not been prepared for differences in the journeys that they and their partner had travelled, especially in the post treatment phase. They had had to accept that the journey had impacted on, and altered their relationships and relationships dynamics and roles. This included the major change where the role of lover had changed, with the partner and patient becoming carer and cared for. No-one had prepared them for how they would feel when this happened, and to cope with the fear that this was a permanent change. They had found an absence of support for their partners and identified the need for formally organised strategies for support of their partners. Together with the issue that support groups, helplines and literature were all heterosexually focussed and non-inclusive. The assumed heterosexuality that they had found led to the 'choreography of disclosure'. However, perhaps one of the hardest things for me to accept as a professional working in this field was that despite all the statements about inclusive and supportive cancer care was the difference between rhetoric and reality. This had left the women living through what could best be described as a dance between realisation of the disease and treatments, normality and their partner

The partners:

In many ways the information provided by the partners formed a mirror to that given by the women, but for this group the data set highlighted that additional difficulties and sense of loss felt by the partners as they had to stand by and watch their loved one go through not only the diagnosis. Together with fear of loss of life, but also what was in some instances permanent mutilating surgery and treatments that left sustained side effects. The main issues repeatedly identified were:

- Loneliness as they travelled their own journey with the women discussing multiple losses. Of self, potentially their partner and of their previous relationship.
- Guilt about having their own needs throughout the cancer journey with their partners.
- A transformed relationship which changed dynamically as the diagnosis and treatment journey progressed.
- Perception of a lack of human skills/humanity (kindness and compassion) and good communication skills demonstrated by the cancer care staff.

For the partners interviewed in this study, the opportunity to openly discuss their feelings was new and in some instances cathartic. The repeated theme of the loneliness they experienced clearly illustrated how they had struggled with the situation in which they found themselves. Circumstances were beyond their control they could only watch and adapt as the situation changed, and try to support their partner while making their own adjustments. Everything in their relationship changed in ways not envisaged. In theory at the beginning they believed they could cope, but the change was much bigger than expected with them seeing themselves becoming carers not partners. This changed dynamic was for some something they could adapt to, as it was 'part of their partner' and therefore changes could and were made as needed. However, for others it led to resentment as it had not been anticipated or they as the journey progressed, they increasingly feared that they would not be able to cope with what was needed. They wanted the situation to remain unchanged and because it couldn't they began to look back, resenting the loss of what they had had.

Not surprisingly some reported feelings of guilt because they had their own needs that were largely ignored by the professionals and being unable to be selfless and completely subjugate their own feelings was extremely difficult. In reality the needed expert support to help them more forwards alongside their partner, while accepting that their own needs had not been wiped out by their partner's illness. This did not mean that they wanted to be sexual

during treatment, but as with the women, the partners stated that they missed the times of closeness and intimacy, because they did not know what was appropriate and what was not. The result of this was both patient and partner feeling lonely within the relationship.

Allied to the above, as regarding having good communication with their partner meant that they were able to become both more sexual and intimate with their partner once the treatment phase was completed. They identified that resuming intimacy slowly and with care and caution had worked for them but would have liked some guidance and support from the professionals. The most shocking thing identified by the partners was their perception of the lack of humanity and care for their needs that they experienced from the professionals. Although they had anticipated/feared homophobic responses from the health care professionals they had not, on the whole had this experience, but many had been treated as friends rather than partners, which negated their relationship, leaving them feeling very much 'on the outside'. They had all been surprised at the lack of appropriate information, both in general terms in specifically for them as lesbian women.

Overall, for me as a researcher it was with an abiding sadness and sense of disappointment that I completed the interviews. The specific area of concern identified by the women and their partners of the lack of being seen as individuals experiencing a very traumatic life event, which was inexcusable. For both the partners and patients there was an identified need for the healthcare professionals to embody the '6 C's' (DH, 2012) and provide true person centred holistic care – rather than cancer being seen as 'just a disease'. This is especially the case in terms of care, compassion and communication. It was hard to accept that regardless of where they had had treatment, these women had experienced the lack of humanity from staff. Although this had been previously identified in the background context to the study and literature review, I had hoped that it would have changed and that at least some of the partners would have had a positive experience. The need to redress the current situation presented yet another element of the educational needs for professionals that needed to be incorporated in the conceptual framework and model regarding professional practice and the impact of cancer and treatments on individuals and couples sexuality, sexual health and relationships.

Chapter Nine: Journey Phase Four (A) - The Conceptual Framework

Positionality: Developing the conceptual framework.

Following extensive gathering of information /data from the lesbian women, their partners and healthcare professionals it had become very clear that a new way of working was needed in regards to the impact of cancer on the patients sexuality, sexual health and relationships. Practice development was urgently required to meet the needs of this vulnerable and marginalised group of women. It was also clear that barriers existed which prevented both 'parties' asking for and providing lesbian sensitive and appropriate care. It was therefore seen as essential that all of these elements, together with potential methods /strategies for practice improvement were brought together within a coherent conceptual framework. The starting point was to explore existing theories by which to explain the findings, to identify gaps in the current knowledge base and to guide the practice development.

Developing the Conceptual Framework

At the heart of any conceptual framework /model for treatment or care plan with patients, and their significant others, is the interpersonal relationship which develops or exists between them and the healthcare practitioners (Angel & Vatne, 2015). Regardless of the professional background, patients expect to be able to develop a trusting relationship with those practitioners responsible for their care (Kitson et al, 2013). Where there is an effective interpersonal relationship between the patient and healthcare practitioner it has been shown to improve both the quality of care given and health - related outcomes, such as improved pain control, shorter hospital stays and better adherence to treatment regimens (Olsson & Hansson et al, 2009, Errasti-Ibarrondo et al, 2015), all of which are essential in cancer care.

The format and nature of the interaction between patient and healthcare professional will vary, dependent upon the professional background and the professional role within the care team. For example, traditionally the doctors' role is primarily concerned with, and focussed on, the disease process and treatment options /regimes. Over recent years there has been a drive towards more patient centred medicine (Bardes, 2012), with some movement towards more holistic management of care with the advent of integrative medicine, particularly within the field of oncology (BSIO, 2015). However, it is still principally based on the medical model of practice (Shah & Mountain, 2007). Within this model a patient's sexuality is seen at best as

being of secondary importance to treating and curing the cancer or more generally not seen as a legitimate part of the treatment plan. This was clearly demonstrated in this study by the medical practitioners in both the expert panel and questionnaire responses, and further reflected in the examination of the current medical training curricula (see page 74).

In contrast to medicine, the traditional nurse patient relationship has been based on a more holistic, person centred model of care, where the development of a trusting relationship plays a crucial and central role. Patients spend much more time with nurses than with other healthcare practitioners and as such the development of an appropriate, professional, 'boundaried' and trust based relationship is crucial (Aranda & Street, 1999, RCN, 2010, DH, 2013). In this study, this perspective was supported by both patients and nurses with **trust** identified as the foundation for any therapeutic relationship (see page 114). Accepting this, and in the light of the changing disease and its accompanying medical and care needs, this trusting relationship has to be dynamic and to change over the period of caring (Weichula & Conroy et al, 2015) Further, it has been identified that if this trust is broken at any point along the therapeutic journey, through inappropriate actions, careless comments or poor practice, this can have a profound and deleterious effect on the individual (Dinc & Gastmans. 2013).

When working with LGBT individuals, a marginalised group who often report having been discriminated against, the development of a trusting relationship is seen to be even more important (Fish, 2010, DH, 2010, Rondahl, 2011). Only once trust has been established can the professional and client /patient work together in order to overcome any potential minority stress being experienced (Meyer, 1995). For the development of any therapeutic relationship it is essential that the practitioners have an understanding of the complexity of their client's needs (Iranmanesh & Axelsson et al, 2009, Wiechula & Conroy et al , 2016), in this case, the diversity of LGBT lifestyles, relationships and specific cancer related LGBT concerns e.g. fertility and childbearing issues and options (see pages 124 and 125) .

A further element to the development of a therapeutic relationship identified by the women in this study was kindness and compassion shown by the healthcare professional (especially nursing staff).The concept of compassion underpins the core essence of nursing being enshrined within the NMC professional standards (2015). As nursing has strived to become more evidence based and to embrace the more highly technical skills required within the modern healthcare arena, it has been suggested that compassion as a core component of nursing has been eroded, with it being seen as aspirational rather than an accurate reflection of current practice (Straughair, 2012, Curtis & Gallagher et al, 2016). Extensive evidence including the Mid - Staffordshire report (2010) and The Parliamentary and Healthcare Ombudsman (2011) has led to the need for the nursing profession to re - endorse compassion

as a core and fundamental nursing value and to place it at the centre of the provision of care (DH, 2010, 2012, 2013, RCN, 2010).

It is accepted that the use of good communication skills; underpinned by the nurses self-awareness and reflective practice is central to the development of the necessary professional, 'boundaried' trust based relationship (Williams, 2008, Arnold & Bloggs, 2011, Mendes, 2015). It has been identified that nurses experience barriers to effective communication, particularly in the difficult field of cancer care, a situation that is compounded when they have little understanding of the lifestyle and emotional needs of their client group (Banerjee & Manna et al, 2015). It may be that these difficulties become apparent when answering difficult questions such as life expectancy, or in the management of angry patients and relatives. It has also been found that nurses and other healthcare practitioners avoid having embarrassing and what they perceive as difficult discussions with patients in regards to their sexuality and psychosexual health (De Vocht, 2011). The result of difficulties in responding or avoidance can contribute to the development of professional anxiety, which will then in turn further adversely impact on their ability to sustain and enhance the needed therapeutic relationship (De Vocht 2011). That this can occur was evident in this study when the nurses expressed the professional anxiety they experienced when assessing and trying to meet patient's sexuality, sexual health and relationship needs. They reported that they doubted both their levels of knowledge and their skills in regards to this area of practice. This reflects the supporting literature (see Chapter Three) but has to be a cause for concern for two reasons. Firstly, this is the group of practitioners specifically tasked with supporting patients /clients as they adapt to the impact that their disease has on these very sensitive and personal areas. Secondly, it would appear that despite the major changes in, and expansion of nurse education (including specialist practice) little major change has taken place in this regards since the early studies of the 1980's. The practitioner's lack of confidence and competence was even more in evidence when they discussed addressing these areas with lesbian or bisexual women.

The practitioners were distressed that their communication and relationship building skills were not sufficient, and therefore had developed a strategy that they referred as avoiding 'unlocking a can of worms'. They reported that this meant that where possible they would not ask questions that could reveal their inability to respond appropriately. They believed that if the client saw them as being unable to 'manage' these issues it would be more damaging to the relationship than if they stayed with subjects that they saw as 'safe'. They appeared to have missed the consideration that the client might perceive this avoidance as a rejection of their specific needs, which would actually be more damaging to their ability to work with similar professionals in the future (Arnold & Bloggs, 2011). Interestingly, a little like their medical colleagues, the nurses felt more able to address the issues if they were able to place them

within a medicalised model for e.g. the use of vaginal trainers /dilators post radiotherapy. It is suggested here that this is similar to Parsons (1951) universal sick role which required patients to conform to medical treatment to restore them to full function in society.

It would seem therefore that the starting point for education designed to enhance, extend and develop practice has to be an assessment by the practitioners of their level of knowledge, skill and 'level of comfort' when discussing personal and /or sensitive issues. Only then can an individual practitioner move on to address areas which are less comfortable for them, in much the same way as a counsellor would work with a client, moving from the least difficult to most difficult areas for exploration (Aldridge & Rigby, 2001, Hough, 2006).

An essential element of good communication within the nurse /healthcare practitioner - patient relationship is respect. The practitioner needs to accept that every individual has their own inherent social and emotional values, and to be able to listen to patients concerns without bias and with respect (Iranmanesh & Axelsson et al, 2009). However, the experiences reported by some of the women in this study showed evidence of stress as they anticipated or feared that they would encounter judgmental, biased and disrespectful behaviour from the healthcare professionals they encountered because of their sexual orientation (often referred to as minority stress (Meyer, 1995, 2003). It is therefore important that healthcare professionals and services are able to assure, or because of previous experiences, re-assure potential and actual patients that they will not be judged or encounter judgemental care. For this to be possible, the practitioners need to have sufficient targeted education about the LGBT lifestyles, relationships and specific aspects of care. Without this it would be difficult for them to feel comfortable and confident enough to provide respectful care. Indeed, the nurses in this study identified, that they do respect their LGBT patients, but they have insufficient expertise, so are anxious of how to 'do things right' and do not want to offend through ignorance which some thought could be construed as maliciousness (Goldberg et al (2011).

The nurse /practitioner - patient relationship has to be mutually constructed, with expectations from both parties as to what constitutes 'appropriate' attitudes and behaviours. This concept has been accepted for decades, Aranda & Street (1999) found that patients may limit the nurses' ability to establish an effective therapeutic relationship by their refusal to be a 'good patient'. Similarly, in her seminal work Stockwell (1972) identified those characteristics which constituted both the 'popular' and 'unpopular patient'. Some of the characteristics of the unpopular patient were their inability or unwillingness to engage with the nurses on a personal basis, giving little indication of their 'sense of self', thus making the development of a therapeutic relationship difficult. However, nearly half a century later, there is still little evidence of this dynamic being included in education and training. Nevertheless, it is argued here that

it must be recognised and further, that it is important for both the practitioner and patient to 'move towards each other' (in the relationship), making the most of being 'in the moment' together. Thus, any conceptual framework or model developed must reflect this process, as only in this way each would be able to learn from each other. They need to mutually ascertain the appropriate way of being within the relationship, rather than on the one hand (practitioner) being anxious and fearful of offending and on the other (patient) being anxious about any anticipated negative judgemental attitude or hostility from the practitioner.

From the data sets from both the healthcare practitioners and the women (who had experienced cancer) and their partners it is clear that within the professional interactions between these individuals different processes were at work. These effect all party's ability to talk about the impact that cancer and treatments have on the individuals and couples sexuality, relationships and intimacy. To make sense of these findings, to seek an explanation for them and to set them within a conceptual framework, further study of existing research information and theory was undertaken. From the wealth of literature that was initially identified, none offered explanations that addressed all the issues and concerns raised. It became evident that there was a need to combine elements from a range of differing theories, models and approaches to develop a new way forward.

From a psychosexual therapy, counselling and education background it was appropriate to review and explore some of the theories of human development as a starting point for ascertaining if any models offered explanation for the findings of the study. The seminal works of Freud (1905 /1977), which form the basis for 'modern day' understanding of human nature were one of the first to be reviewed. The theories of mind development and functioning e.g. the id, ego and super ego, along with concepts such as transference and countertransference, together with defence mechanisms including projection and repression resonated with the findings from both the women and the health care professionals in this study. These go some way to explaining the 'forces at play' within the professional interaction /relationship. However, Freud's (1905 /1977) theories on individual psychosexual development and thus human development as a whole, where all behaviour is driven by the libido and controlled by the ego and super ego were seen to be too sexually focussed. Further the theory stipulated that an individual's psychosexual development was completed during adolescence, thus failing to take account of the changes which take place during early adulthood, a time when many health care professionals commence their professional journeys, with the inherent learning which takes place during this time.

Freud's (1905 /1977) views on homosexuality, which according to his theory of the oedipal complex the heterosexual outcome was the "normal" resolution, while the homosexual

outcome represented arrested sexual development, have over time been seen as 'damaging' to individuals from the LGBT community. Whilst Freud did not believe that homosexuality was a mental illness he did believe that it was amenable to treatment, leading to the history within the LGBT community of 'forced conversion' and the development of mistrust of health care professionals by some older people from the LGBT community. There is therefore the potential that Freud's theory of psychosexual development as part of the conceptual model would not be viewed positively by members of the LGBT community. In addition, Freud (1905 /1977) does not directly address the impact of critical illness on the personality, an omission seen as important given the nature of this study. The health care practitioner would need to possess extensive knowledge of defence mechanisms and coping strategies, together with an understanding of and the ability to work with transference and countertransference within the professional relationship. This is seen as too ambitious for the development of healthcare practitioners working within the cancer settings. It is important to remember however, that the majority of subsequent psychological development theories built on Freud's (1905 /1977) works through extensive critique and reformulation of central ideas and as such his ideas and work are still extensively used within the psychotherapy world.

Moving on to a more recent approach, Bandura (1977, 1986) proposed the Social Learning Theory (SLT) and Social Cognitive Theory (SCT) as an alternative explanation of human development and behaviour to those offered by Freud (1905 /1977), building upon the behaviourist theories of Skinner (1953). SCT posits that individuals learn through observing the behaviour, attitudes and the consequences of behaviour of other people. It explains behaviour in terms of a continuous, reciprocal interplay between cognitive, behavioural and environmental factors (reciprocal determinism). In addition to the observation of behaviour, Bandura (1977, 1986) argues that learning takes place through the reinforcement (either positively or negatively) of copied behaviour, together with the observation of rewards and punishments, that is by vicarious reinforcement. Learning, it is suggested takes place as a result of imitation, modelling, observational learning, reinforcement (positive, negative and vicarious). SCT also takes into account bidirectional influences (from parents to child but also from child to parent), which has been extended by the ecological theorists, such as Bronfenbrenner (1977, 1979, 2005) to include the bidirectionality of social influences on the developing individual. It is this extension, to include the impact of the wider environmental factors which meant that the ecological social model of Bronfenbrenner (1979, 2005) was seen as more appropriate in partly explaining the findings from within this study.

The relationship between the healthcare professional and the person effected by cancer is seen as mutually constructed, with both parties learning from each other - hence the bidirectionality of learning. Furthermore, the impact on the relationship of the wider cancer

care environment cannot be underestimated. It was interesting to note that some of Bandura's (1977, 1986) ideas were originally postulated by Lewin (1935, 1951), therefore Lewin's works were revisited and reviewed. Challenging and to some extent building upon Freud's work, Lewin (1935, 1951) developed his field theory to explain human development. One of the core aspects of this theory is that human behaviour is the function of the individual and their environment, which are interdependent variables. That is they mutually and continuously influence each other. The interaction of all the personal and environmental factors is known as the psychological field or 'life space'. The field or life space contains the individual's biological and psychological aspects together with their environment with its social relations and physical dimensions. Lewin (1935, 1951) argues that the individual's 'life space' develops over time, with previous experiences impacting upon a current situation. More recently it has been suggested by Bronfenbrenner (1979, 2005) that for Lewin, behaviour implies a static concept in which only the present field forces (the present) matters, not the passage of time. However, the importance of time and maturation are seen as crucial to our understanding of the dynamics being brought into play within the professional practitioner - patient interaction. This is because both the parties will have been moulded by their experiences across time, including socialisation, personal and professional regarding sexuality (including homosexuality) and their place within healthcare. As will be seen below, Bronfenbrenner (1979, 2005) incorporates within his model the kinds of changes that characterise development over extended periods of time. Not only for the individual but also their interaction with a changing physical, social and cultural environment. This shift in the societal and cultural environment is seen as important in regards to the changes which have taken place over time in regards to homosexuality and same sex relationships which will have shaped the development of both the lesbian women and the practitioners within this study.

The Conceptual Framework

On completion of this review, none of the theories offered a full explanation of the findings of this study. Therefore, elements of a small number of models and theories were selected as offering appropriate contributions to the proposed conceptual framework. These included Bronfenbrenner's (1979, 2005) social ecological theory, minority stress theory (Meyer, 1995, 2003), professional anxiety (Benner, 2001) and the concept and theories of taboo, for example those in relation to cancer, sexuality and homosexuality. Although these theories alone did not offer an explanation for the experiences of the women and /or the practitioners within the study, elements within them could be used in combination to develop a dynamic process for professional, interactive communications, and to demonstrate how each is 'played out' in the

professional nurse/practitioner - patient relationship. To demonstrate how they have been combined in an incremental process the starting point has to be a discussion of how and why each has been selected and where they fit within the total model.

Bronfenbrenner's social ecological theory

As outlined in the section on positionality in chapter one for the purposes of the study it was important to myself as a healthcare practitioner to increase my understanding of the world as it is perceived by the patient and their significant others. The healthcare professionals in this study have the same needs, just as my work demands that I try to understand the client's psychosocial upbringing, what has made them the person they are, and how are they likely to respond in a care giving situation, so do those in this study. Therefore it is important to have an understanding of the 'other's' (the patients) ecological system. Bronfenbrenner's model (1995, 2005) resonates both with this, and in methodological terms with the principle tenets of phenomenology, the underlying epistemological stance underpinning this study and was therefore seen as an appropriate element of the conceptual framework.

The social ecological or ecological systems theory (see Figure 9) was developed by Bronfenbrenner as a theoretical model of human development (Bronfenbrenner, 1979, Bronfenbrenner & Ceci, 1995, Bronfenbrenner et al 1996, Bronfenbrenner, 2005). Having identified a gap in the previous works, Bronfenbrenner built upon the earlier works of psychologist's such as Lewin (1935, 1951) Bandura (1977, 1985) and Vygotsky (1986). Bronfenbrenner sought to recognise and place greater emphasis on elements which had been previously underplayed within theories of human development. It focussed on the impact of the environment in which the individual grows and develops, which Bronfenbrenner (1977, 1979, 2005) viewed as bidirectional, such that layers of the environment and the individual can influence each other. Together with the changes occurring over time, to both the individual and the environment. Furthermore, the model allows for variables or components in the ecological system to interact with each other. As a result of the complex and interactive nature of the different levels, Bronfenbrenner (1979) refers to each level as a system.

One of the principle ideas of the model is that an individual interacts with their environment, at different levels, ranging from proximal e.g. parents /family to more distal e.g. social political, cultural norms or laws. Bronfenbrenner (2005) argues that that the proximal processes are the primary engines of an individual's development. It is, therefore suggested that the formation of strong beliefs and attitudes within the family become deep seated and difficult to change in later life. Furthermore, the interactions between the individual and their environment result in the construction of the 'individual ecological niches', these are what an individual experiences as their world. The result of this is that human beings bring to any situation their own

perceptions, interpretations, feelings and expectations - their own world view. Muuss (1995) suggested that a potential danger exists when different microsystems espousing divergent values meet. If an individual's sexual feelings and peer group are seen negatively or punished by their parents, school and or church this will give rise to personal dissonance and the potential for these individuals to possibly develop internalised homophobia and minority stress.

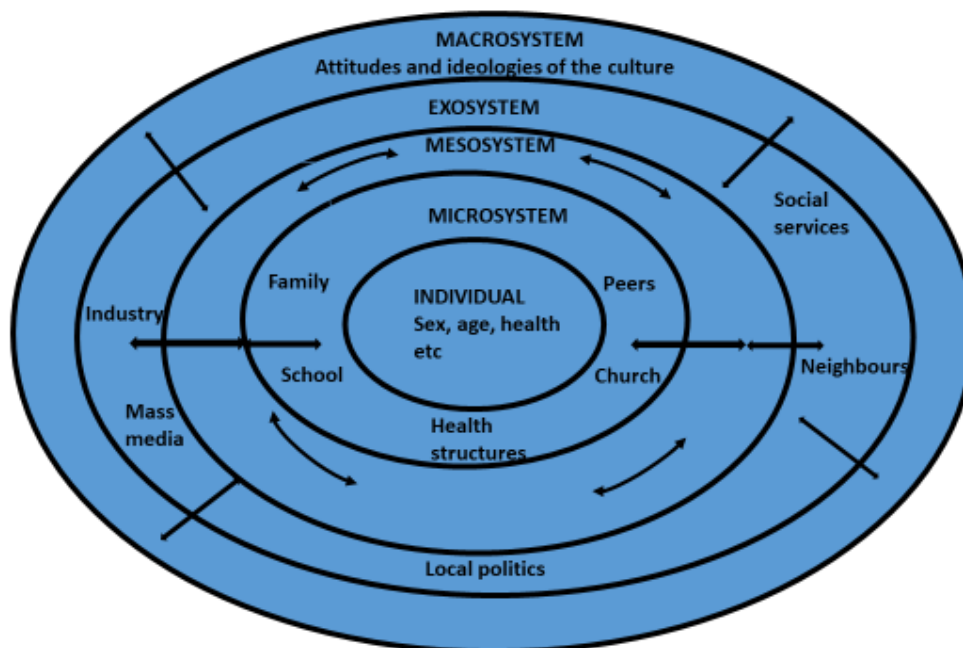


Figure (9) Bronfenbrenner's social ecological theory

Figure (9) above indicates the first level, the microsystem refers to those individuals, institutions and organisations which directly impact upon a developing child /individual and includes parents, family, school, friendships and peer groups, neighbourhoods and religious institutions. Further, that this microsystem incorporates the individual's beliefs, values and attitudes together with their personality and differences (Henderson et al, 2009, Armstrong & Reissing, 2013). The second layer, the mesosystem includes the interrelations between the major settings in which the individual finds themselves. The interactions between for examples the family and teachers, between the child's peers and family. It also includes the connections between the individual and important others in their life's such as romantic partners. The third layer, the exosystem contains larger networks that may extend some influence on the individual but that also may affect the mesosystem. It involves links between a social setting or context within which the individual does not take an active role and their immediate situation. Examples include friends, extended family, neighbours or media. The final layer is the macrosystem, includes the social and cultural ideologies and beliefs within which the individual

lives (including laws and religious beliefs). The macrosystem contains the overarching structural or societal norms which influence multiple aspects of an individual's life. Surrounding or running through model is what Bronfenbrenner (1974) originally termed the chronosystem.

This reflects the impact of the passage of time, both for the individual and for society at large. It reflects the cumulative experiences a person has over their life course (Bronfenbrenner, 1974) emphasises the interplay between the characteristics of a person and the social context in impacting on development over time, hence in later iterations of his model Bronfenbrenner (1995) referred to the model as being a 'person- process- context- time model'. This was seen as important when looking at professional practice and the development of practitioners, as any model of practice needed to be dynamic therefore the stages of practice identified below were developed. As practitioners could move through these at different stages of their professional practice /life.

Extrapolating from this, and linking with the findings of this study, it would seem that one of the aspects of professional practice identified as being crucial when addressing an individual's sexuality and psychosexual health is the practitioners level of comfort, and ability to self-assess their knowledge, skills and attitudes (self-awareness). For this they need not only the ability to critically analyse their practice, but to be able to utilise this self-awareness in relation to the subjects they are going to discuss, in this case sexuality, intimacy and relationships, they need to have sexual self- awareness. Together with the skills to communicate this self-awareness within the therapeutic relationship. When meeting the care needs of individuals from the LGBT community, the practitioner has to be aware of their beliefs and attitudes towards same sex relationships and be willing to examine the potential impact of these on the practitioner - patient relationship and quality of care provided. Thus, in Bronfenbrenner's (1995) terms the practitioner has to be aware of their own ecological system, and how this impacts on communication.

Applying this to practice when a patient and healthcare practitioner interaction takes place their two world views are brought together and while they do not necessarily match, it is important that they do not collide. If the two different world views do collide in the inter and intrapersonal dynamics within the professional interaction, the needs of the patient and /or partners are /may not be met. The practitioner needs to know and accept that the patient may anticipate a negative response from the health care practitioner based on their perceptions, expectations and in some instances previous experience. The responsibility for anticipating this and preventing further negative practitioner behaviours, which can cause minority stress, lies with the professional, but without understanding and 'accepting' their own ecological processes they may be unable to do so. For instance, the healthcare practitioner may hold

views regarding both the legitimate place of sexuality and LGBT issues within their practice, through their professional socialisation and their upbringing with regards to LGBT individuals and their relationships. In addition, it is important to recognise that within both the practitioners and patients ecological systems and directly impacting upon their values, beliefs and attitudes is the influence of social and cultural **taboo's**, yet another concept that needed addressing in the now developing conceptual framework.

Systems and strategies need to be developed to enable practitioners to explore their understanding of the impact of cancer and its treatments on an individual and /or couples sexuality, psychosexual and relationship 'health'. This has to include reflection by the practitioner on the antecedents of their own values, beliefs and attitudes related to these aspects of being human. That is to say, what constitutes their personal ecological system in respect to sexuality, same sex relationships and sexual intimacy. The purpose of this is for the practitioner to become aware of the elements of their own ecological system which could potentially both enhance the practitioner - patient interaction and those which would present barriers to the development of the practitioner- patient - relationship. To become aware of how the latter could negatively impact on the quality of the care they provide to patients and /or partners, there needs to be a change in the current education process, as professionals are rarely asked to consider how they bring to any interactions their own personal history and ecological system, or how it will directly impact on their working relationships.

It also has to be accepted that as evidenced by some of the women in this study, previous negative experiences with healthcare professionals and internalisation of these may lead to a reluctance to approach health care practitioners or ask for assistance from them, even when this is needed. The patient's ecological system has been permanently impacted upon, and this will have affected their expectations of healthcare professionals and what they can offer. For women from the LGBT community, each with their own personal ecological system, a practitioner's inability to meet their expectations of care can be interpreted as being the result of homophobia and heterosexism. It has to be accepted that in some cases this interpretation may be well founded, whilst in others this may not be the situation at all. In either case as the patient cannot assess the professionals background or reasoning the quality of the care is directly affected, which given the 'long haul' of the cancer journey is not a suitable position for either the patient, partners or the plethora of healthcare staff involved.

In contrast to this group, are those who have had limited contact with health care prior to their diagnosis of cancer. This group may present a different problem, as it has been recognised (Lateef, 2011) that generally patient expectations of healthcare have risen over recent times, with the practitioners sometimes struggling to meet these expectations. This can lead to unmet

expectations adversely impacting upon the practitioner - patient interaction, which in turn can lead to the patient losing trust, and viewing the practitioner with scepticism and intolerance, so starting a downward spiral with the professional relationship and further changing the ecological systems of both. The influence of and the interplay between the patients and practitioners ecosystems within their interaction /professional relationship is shown in Figure (10)

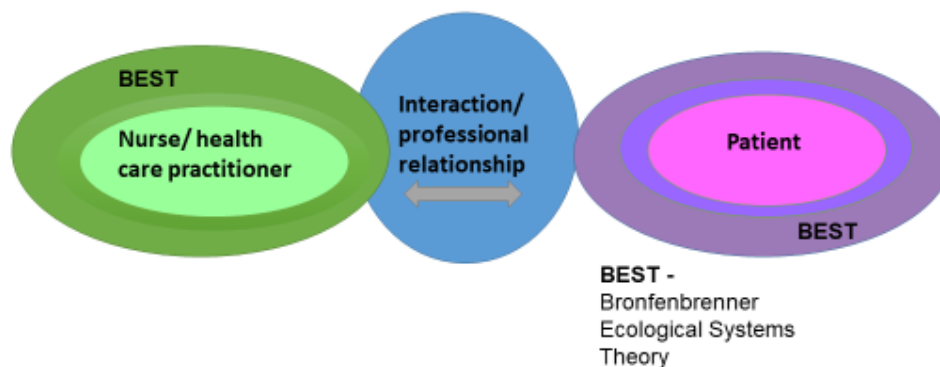


Figure (10) impact of Bronfenbrenner Ecological Systems on the professional practitioner – patient relationship

Minority stress model

Whilst the ecological model discussed above, fits with key issues from the findings, it does not address the issue of minority stress raised by the women in this study. Therefore, a way had to be found to incorporate this into the developing conceptual framework. Adopting a social constructionist perspective Moss (1973) and Meyer et al (2003) have argued that interactions with society provide individuals with information on the construction of the world. They further suggest that an individual's health is compromised when there is incongruity between this information and a minority persons experiences in the world. In addition, Allison (1998), Clark et al (1999) and Meyers et al (2003) argue that an extensive and significant level of stress is experienced by individuals from stigmatised minority groups where there is dissonance between the individual and the dominant culture. They see this as being at the core of minority stress, and experienced by marginalised groups within society. Despite the changes in societal attitudes and mores over the past decade in the UK many individuals

within the LGBT community have had direct experience of this incongruence whilst growing up and may continue to do so on a day to day basis.

Herek (2000), Cochran (2001), Myers et al (1995, 2003), King & Semlyen et al (2008) and Semlyen & King et al (2016) have all argued that the concept of minority stress when applied to the LGBT community may lead to negative or adverse mental health outcomes. By way of explanation Meyers (1995) and Meyers & Dean (1998) have postulated that four processes of minority stress are brought into play in the psychodynamics of individuals from the LGBT community. These they explain are, external objective stressful events (e.g. experience of prejudice or homophobic violence) both acute and chronic, the expectation of such events, together with the vigilance this expectation requires and the internalisation of negative societal attitudes (internalised homophobia). Finally, they and others (Pennebaker, 1995, DiPlacido, 1998) suggest that concealment of the individual's sexual identity is linked to a variety of stress processes which form part of the minority stress experienced by individuals from the LGBT community. Some people may be vigilant in interactions with others, with the expectation of rejection, and hide their identity for fear of harm or internalised homophobia.

During the development of a professional, therapeutic relationship between the healthcare practitioner and the person affected by cancer, both parties bring with them a degree of stress or anxiety. Minority stress suggests that LGBT people experience an inherent stress due to society and services being geared towards and favouring those who are heterosexual or cisgender. It also involves the impact of the **taboo's** which have and to some extent still do exist regarding homosexuality and same sex relationships. Thus, when an individual from the LGBT community, such as the women in this study come into contact with the health system and health care professionals they carry with them, to a greater or lesser extent the burden of minority stress. Together with the expectation of and vigilance regarding prejudiced and homophobic reactions and treatment by staff. This was clearly demonstrated by a number of women in this study, who had anticipated and mentally prepared for a 'battle' with the health care staff to have their partners included in the care and treatment discussions and decisions. Fortunately, these anticipated negative responses had not been the reality for these women and they may also not be the case for other lesbian women. However, this was an additional stressor at a naturally very stressful time for both the women and their partners. The very possibility of the impact of such additional stress cannot be ignored and this has to be included in each stage of the conceptual framework together (as shown in Figure (11) below), with strategies to enable practitioners to provide high quality, appropriate support.

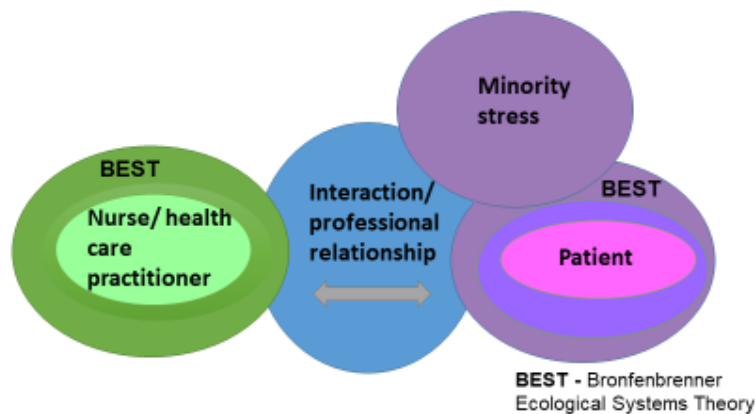


Figure (11) Impact of minority stress on the professional practitioner – patient relationship

Professional/s 'anxiety'

A further issue vocalised in this study that has to be addressed for effective communication between professional and patient is 'professional anxiety' (see Figure 12 below). The anxiety of the practitioners that they could not provide good 'enough' practice 'do things right' revealed their concern that they would not meet the standard of practice and code of conduct which govern their registration, and which are based on the principles of ethical practice (NMC 2010). Two of these important ethical principles guiding and underpinning healthcare practice are beneficence and non-maleficence (Burkhardt & Nathaniel, 2007).

Beneficence is the idea that the practitioner's actions should promote 'good', thought of as doing what is in the patient's best interests. Whilst non-maleficence asserts that one should do no harm to patients. This principle acts as an obligation for health care professionals to safeguard their patients from harm by removing or preventing harmful situations and promoting non-harmful ones. When entering any health care interaction with patients the practitioner carries with them these ethical obligations, enshrined as they are in their professional code/s of practice. Therefore, the practitioner can experience a degree of professional anxiety arising from their own professional expectations that they will be able to provide evidence based non - judgemental, culturally sensitive and appropriate care (GMC, 2013, NMC, 2015). Further, as identified in the supporting literature when addressing the impact on patient's sexuality of cancer and treatments, there is can be an expectation from patients that sexuality will be broached with them, by members of the healthcare team during their treatment period. As discussion has previously demonstrated, many of the practitioners in both the expert panel and specialist nurse focus group, whilst recognising the importance

of meeting the patients' needs in regards to their sexuality and psychosexual health felt ill equipped to do so. Their concern being that they had neither the knowledge nor skills to address these areas, in general and more so when related to LGBT individuals, demonstrates the lack of a comprehensive model for them to follow in practice. To leave them to attempt to address these areas without appropriate training would clearly be in breach of the professional codes of practice (NMC, 2015, GMC, 2013). Therefore practitioners require role specific education and training in both the general aspects of addressing their patient's sexuality and psychosexual health needs. Further, to help practitioners to avoid heteronormative practice elements should be developed within the education and training to address the LGBT specific areas of care.

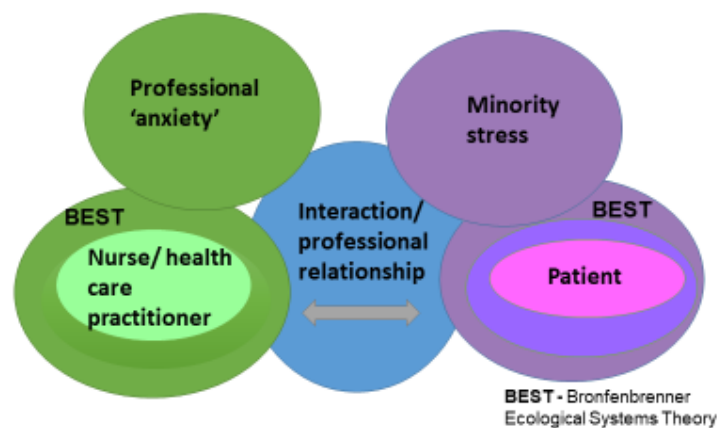


Figure (12) Impact of professional 'anxiety' on the professional practitioner – patient relationship

Taboos

Since the introduction of the word into Western society by the explorer James Cook in the 18th century, the word taboo has become common parlance. Originally the word was used in reference to forbidden behaviour that was believed to be dangerous to individuals or society as a whole (Holden, 2000). Burrige (2015) suggests that since the early days of human existence, in all societies' subjects such as bodily functions, sex, lust, disease and death have given rise to prohibitions and taboos. She further argues that taboos are dynamic, and notions about what is forbidden will change across cultures and across time. Taboos are seen as playing a crucial role in our own or indeed any society, determining how people must or must not behave. Furthermore, it is argued that the ritual imposition of taboos is symptomatic of a need for order and a desire within societies to make the world conform to an abstract view we have of it.

Without clear, strict boundaries there is a real fear that society would descend into chaos (Holden, 2000). This concept of taboo has been explored by academics and practitioners for many years, from a range of disciplines ranging from anthropologists (Steiner, 1956 /2004, Leach, 1964, Douglas, 1966), through psychologists (Freud 1856 /1939) to linguists (Burridge, 2015, Goa, 2013), each offering their own discipline based explanation of the origins of taboos, their role and importance within the functioning of society.

In the last century Douglas (1966, 1970) proposed the idea that taboo's arises from the notions of what is seen by society as 'dirty' and 'pure', with taboo stemming from those things which are seen to be dirty. She further suggested that things seen to be dirty were sources of contagion or disease, feared by individuals within society for example incest. One of the great taboos of recent times has surrounded cancer (Karbani, Lim & Hewison et al, 2011) and the fear of this disease. It has been argued that a taboo word is avoided not because of any fear that physical harm may befall either the speaker or the audience, rather that the speaker may offend the sensibilities of the audience causing embarrassment and discomfort (Karbani, Lim & Hewison et al, 2011). In the case of cancer and sexuality different taboos come into play compounding the problem. When given a diagnosis of many types of cancer in resource rich countries it is no longer regarded as a death sentence, but people remain fearful of such a diagnosis and in some instances even talking about cancer still carries a cultural taboo (Karbani, Lim & Hewison et al, 2011).

Then too, in western culture, sex and sexuality are also seen as great taboos (Goldenberg & Cox et al, 2002), in part fuelled by religious and cultural prohibitions. There are many aspects of both sex and sexuality with tight 'controls' including appropriate and inappropriate sexual acts, appropriate times for sexual activity and the gender and numbers of individuals taking part in any sexual activity (Goldenberg & Cox et al, 2002). In many cultures and religions homosexuality is forbidden and often punishable, sometimes even by death (Stonewall, 2016). In his seminal work Leach (1964) argued that individuals learn to differentiate 'self' from 'other' and that taboos occur whenever there is a danger of these becoming confused, causing personal dissonance and discomfort. Using this rationale it therefore can be suggested that the taboos surrounding cancer and sex result from the threats to 'self' they represent to the individual. Douglas (1966) postulated that where a society is marked by subordination of the individual to authority with, severe restrictions on behaviour this leads to the existence of many taboos. She further suggested that groups of individuals create a boundary between themselves and the outside world. Where a group is strong, its boundaries must be protected from outsiders and outside beliefs by magic and taboos. It is argued here, that health care professionals (including nurses) maintain their professional boundaries with taboos around sexuality being a legitimate part of their practice. This questioning of the legitimacy of their views regarding sexuality within healthcare practice was clearly identified within the supporting

literature and the discussion. In addition individuals from the LGBT communities can also have boundaries to 'protect' their communities and themselves from outsiders. Historically, taboos existed regarding homosexual behaviour and relationships, with the hidden nature of these relationships being kept hidden for fear of persecution and infringement from the 'outside' heterosexual world. It is suggested that for some LGBT people these taboos still exist and are brought into play in their interactions with healthcare professionals.

In Figure (13) taboo has been included in the professional - patient interaction. It stretches into both the ecological systems of the patient and the professional. Plus it is presented as a sharp and angular rectangle placed at the bottom of the model, as a symbolic representation from which point taboos can 'trip up' and have a harmful effect on both the patient and practitioner.

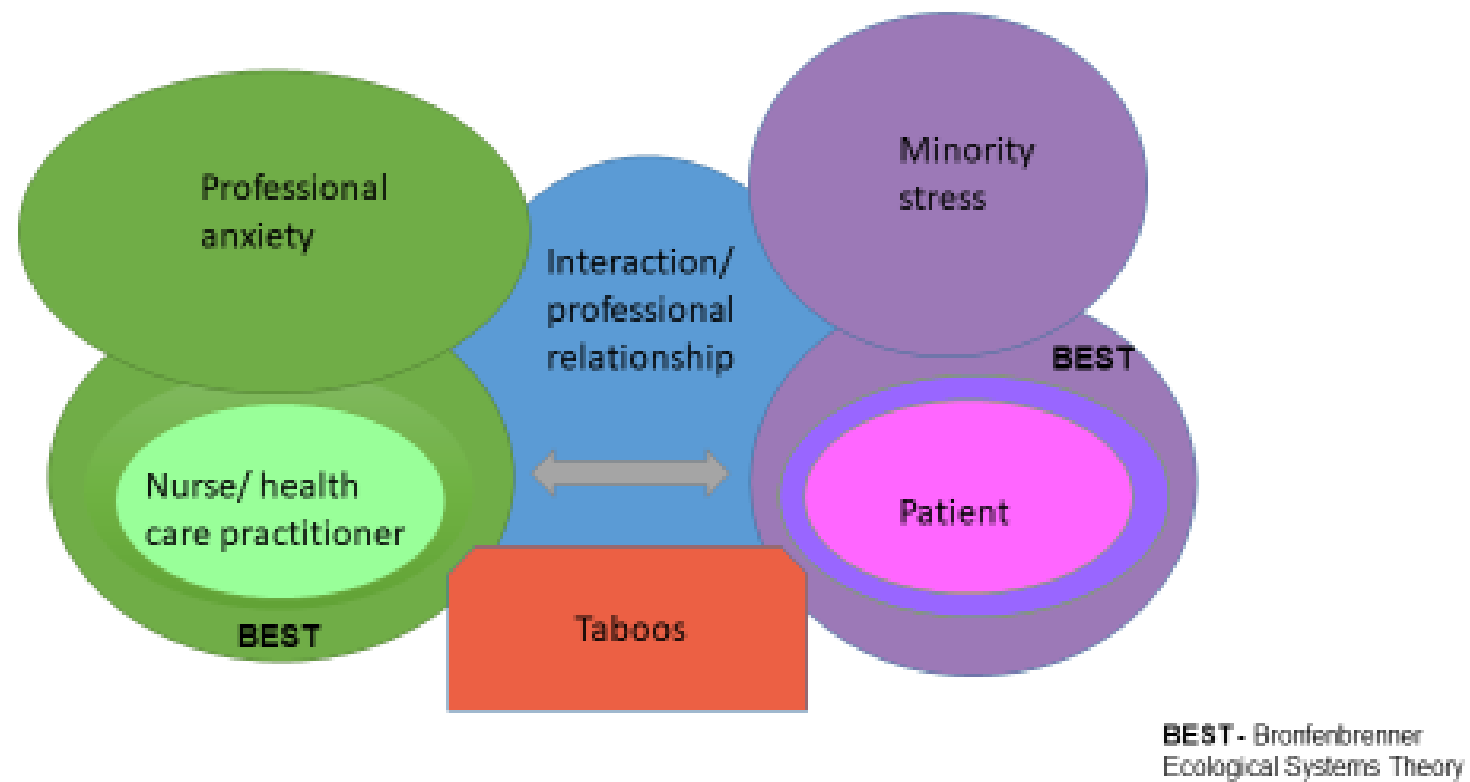


Figure 13: The conceptual framework

The overall conceptual framework presented above in Figure (13) has been formulated in the light of the findings of this study, offering a new and sustainable model for practice. It is based on the dynamic and evolving nature of inter and intrapersonal dynamics, showing how they fit together in professional interactions, either blocking or facilitating a meaningful relationship. This is one in which both the individuals affected by cancer and the cancer specialist practitioner feel able to appropriately discuss any issues or problems being experienced by the individuals in respect to their sexuality, relationships and intimacy. It is the development of this type of meaningful relationship to which practitioners and professional education should be striving.

The model is needed because the dynamics of the nurse patient relationship have changed over recent years, with the increased throughput of patients and shorter hospital and outpatient periods. Together with increasingly complex co-morbidities, requiring nurses with a higher skill level (Errasti- Ibarrondo & Perez et al, 2015, Banerjee & Manna et al, 2016). This has led to less time being available for nurses to develop the empathetic, trusting and confidential relationship with patients they need when working with the impact of cancer on the patients' sexuality and psychosexual health. This impacts on the different levels of practice, competence and practitioners all of whom have differing roles with the patient. They need education and training that matches their level of practice, own levels of comfort when addressing these areas with patients, their own ecological systems and their role and level of practice. As will be outlined below (Figures 14, 15 and 16) these levels of education and practice will aim to bring the concentric circles of the patient and practitioner closer together, foster greater understanding of each other and the care needs of the patient, lessen the impact of the taboo's outlined previously and diminish the levels of minority stress and professional 'anxiety' experienced.

The professional participants within this study identified their need to develop and possess an awareness, understanding and skills in several main areas namely:

1. Greater personal sexual self-awareness.
2. The diversity of LGBT lifestyles and relationships.
3. The impact of cancer and treatments on the sexuality, psychosexual and relationship of the individual with cancer and their partner/s. Both heterosexual and LGBT.
4. Understanding of the LGBT specific aspects of cancer care in relation to the above, to overcome heteronormative practice.
5. Specific communication and counselling skills to address these areas of practice.
6. Signposting to appropriate resources and services.

These elements constitute the basic components of a training and education programme / package to be developed for all levels of practitioner. The depth of knowledge, skills and competence increasing within each level of practice.

Practice level one (basic level)

It is suggested that at the most basic level all healthcare practitioners working in cancer care should possess the necessary knowledge, skills and attitudes to deliver non - judgmental and LGBT sensitive care to patients and partners who are affected by cancer and treatments. This being the case both generally and importantly in relation to the sexuality, psychosexual and relationship aspects of care. Healthcare practitioners need to have the confidence and competence in their practice to reduce their own professional anxiety and to help to reduce the patients and /or partners minority stress.

Case study: Male oncology nurse working in a large specialist oncology unit:

“I’m not very confident I know sometimes people find it difficult especially a male nurse and being? They will skim over things or even in pre assessment I’ll explain you know, that there are things out there but it is difficult I find it difficult. That may be just confidence, but also maybe if they come back with a question I can’t answer I would just have to say that my own knowledge was just poor.”

[HCPFg Participant 2(f)]

Case study: Female chemotherapy nurse working at a provincial hospital:

“Need understanding of different sexualities and how to ask difficult questions. Understanding the needs of different sexuality groups and what they are? Skills - good interpersonal skills e.g. listening, paraphrasing etc.”

[HCPFg Participant 2(h)]

They need to feel comfortable and competent to ‘allow’ these areas of care to be ‘on the table’ for discussion with resultant appropriate action being taken - including referral onto a more qualified practitioner. In some regards this level of practice can be equated with the permission giving stage of the PLISSIT model (Anon, 1971) of sexuality practice, which has been previously advocated by the RCN (2000). However, unlike the PLISSIT model the starting point for practice is the practitioner’s level of sexual self- awareness and understanding of the diverse nature of individual’s relationships.

Through a basic training /education programme the practitioner should be able to reduce their own professional anxiety, and be able to reduce the patient’s minority stress, by providing

more LGBT sensitive care. With a greater awareness of their own ecological system and the impact of taboos pertaining to cancer, sexuality, same sex relationships and sex, the potential negative impact of these on the practitioner - patient relationship and interaction can be reduced.

For many practitioners this level of education should be sufficient for both their role and their own level of comfort when discussing the impact of the patient's cancer and treatments on their sexuality, psychosexual and relationship health. As shown in Figure (14) below, for these practitioners it is appropriate for them to professionally exit at this point of the patients care and if necessary refer them on to a more experienced and trained colleague. This is also true with the other two more advanced levels of education and practice.

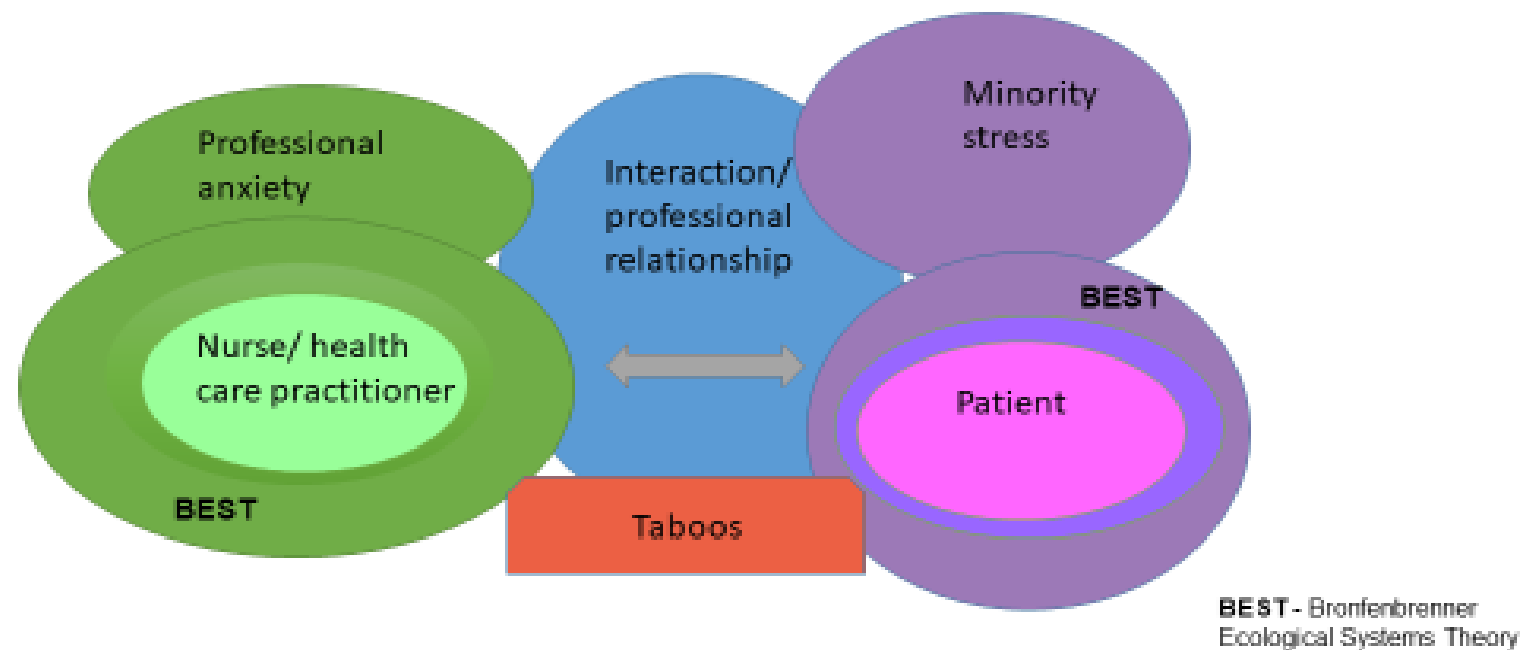


Figure 14 Conceptual framework – following utilisation of education programme by health care professional (Basic level practice)

Practice level two (intermediate level)

It has been recognised that due to the time constraints and the speed with which theory and practice change make it difficult for nurses and other practitioners to keep up to date in all aspects of their practice area. Even though this is essential to meet the both the requirements of professional codes of conduct and the quality and safety of care (Pagnamenta, 2005). Over time this led to the development of link nurses in areas of practice such as infection prevention and control and tissue viability. Link nurses possess more advanced knowledge and skills in their area of practice (Tinley, 2000, RCN, 2012,). It is therefore proposed that the second level of practice is that of link nurses /practitioners. These staff would have a greater depth of knowledge and increased skills in the area both the impact of cancer of sexuality, psychosexual health and relationships generally **and** related to **LGBT specific** elements of care. These link practitioners will also possess a greater degree of comfort with working the topic area and working with patients to meet their sexuality, psychosexual and relationship needs. In today's NHS it is frequently impossible for a specialist nurse to assess and plan the care of all individual patients, the link practitioner will work closely with the specialist nurses and have access to the specialist team. The link practitioner would act as a role model and local 'leader' and visibly advocate for the inclusion of the patients sexuality and psychosexual health needs within their care plan. In addition they, through both their role modelling and clinical education opportunities, should enable other staff to learn and develop their practice in this area. One of the elements identified by the professional participants of this study was the need for ease of access to resources (including signposting information) that they could use with patients and /or partners. Therefore, one of the areas of link nurse responsibility would be the development and updating ward /unit these resources. In terms of the conceptual framework, the level two practitioners would be a resource and referral point for the level one practitioners. That is to say, that if the level one practitioner feels unable to address the complexity of patients and/or partners care needs in regards to sexuality, psychosexual health and relationships, or feel uncomfortable in terms of their own ecological system to do so, they have another practitioner to whom they can sensitively refer the patient on to. Indeed, as shown by the participants in this study this happens informally within some care teams in terms of those practitioners who do not feel comfortable talking about sex and sexuality referring to colleagues who are more comfortable. Thus, the development of a link practitioner role is in keeping with this finding. However, it needs to be recognised that some practitioners, having undertaken a level one training /education programme together with their degree of self - awareness and comfort may be equipped to work and wish to 'offer' themselves as an informal

support resource to colleagues without undertaking any further education/training or becoming a link practitioner.

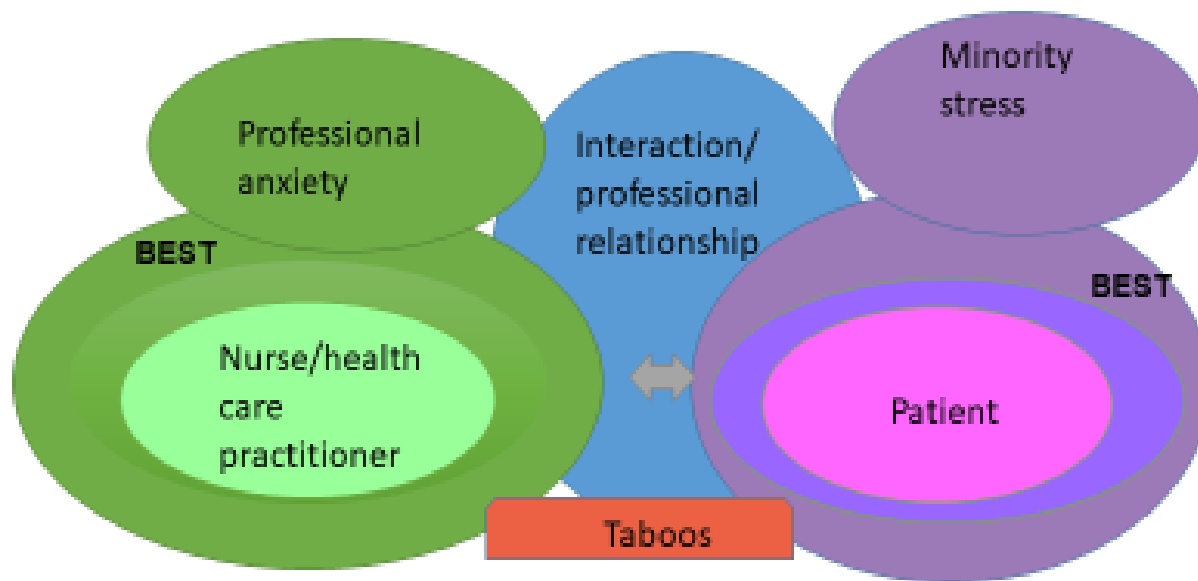
The education programme for these practitioners needs to include enhanced communication skills as advocated by the practitioner below:

Case study: Female chemotherapy nurse working in a larger regional, specialist centre:

“Education on ways of building a rapport with patients and advice on how to enable them to feel they can talk to you about anything concerning them, creating an open environment.”

[HCPFg Participant 2(d)]

As with level one practice, as shown in Figure (15), the aim of the education programme for this level of practice is the **further** reduction of their own professional anxiety and the patient’s minority stress, via a greater awareness of their own ecological system, the possession of more advanced knowledge and skills. Together with a greater awareness and rejection of the taboos pertaining to cancer, sexuality, same sex relationships and sex. The result being the further reduction of the negative impact of these on the practitioner - patient relationship.



BEST - Bronfenbrenner
Ecological Systems Theory

Figure 15 Conceptual framework – following utilisation of education programme by health care professional (intermediate level practice)

Practice level three (advanced level)

The final level of practice would be that of a specialist practitioner in the area of cancer related sexuality, psychosexual and relationship health, both generally and addressing the specific needs of individuals from the LGBT community. This practitioner could act as a mentor, resource person and referral point for the link practitioners and a resource person and resource for other practitioners. In some senses the role could be undertaken by the cancer care specialist nurses, as they would already have a closer practitioner - patient relationship than other more general ward or unit based staff. Indeed an integral part of their role is the ongoing support from diagnosis, through treatment and for a time after completion of treatment of patients, partners and families (Skilbeck & Payne, 2003, National Cancer Action team, 2010). However, as was shown by the specialist practitioners within this study, these specialist nurses do not feel equipped to undertake the sexuality, psychosexual and relationship health care needs of patients generally and specifically in regards to LGBT individuals.

Case study: Female oncology specialist nurse working at a large specialist centre

“we become more privy to their life is, so it would just be it suppose for me to know about these issues rather than just think, oh god I don’t know how to handle this or um.”

“I worry that I don’t have the right communication skills to ask about difficult topics. I know I deal with difficult subjects, like cancer and the patients concerns about outcomes of treatment, dying and all that. But talking about sex feels different somehow, especially if I’m talking to gay people - I don’t want to say something wrong!”

[HCPFg Participant 2(e)]

They would therefore need a more in depth level of awareness and knowledge of these areas, advanced communication and counselling skills together with specific therapeutic interventions to be utilised to address the patients and /or partners care needs.

It could also be suggested that due to the time constraints experienced by specialist nurses, the personal nature of the care area, together with the degree of personal self - awareness and comfort in talking to patients and partners about sexuality, psychosexual and relationship needs that this level of practice should be undertaken by another practitioner who is part of the multidisciplinary team. It is important that the levels of practice and the education programme developed for each are not confused with the existing hierarchy within healthcare practice. The crucial thing is for the practitioner to have high levels of self - awareness, knowledge and advanced skills - developed through an advanced level education programme to feel confident and competent to address the patient and /or partners care needs. Thus, reducing still further the impact of minority stress, professional anxiety, personal ecological systems and taboos on the practitioner - patient relationship and interaction - as shown in Figure (16) below.

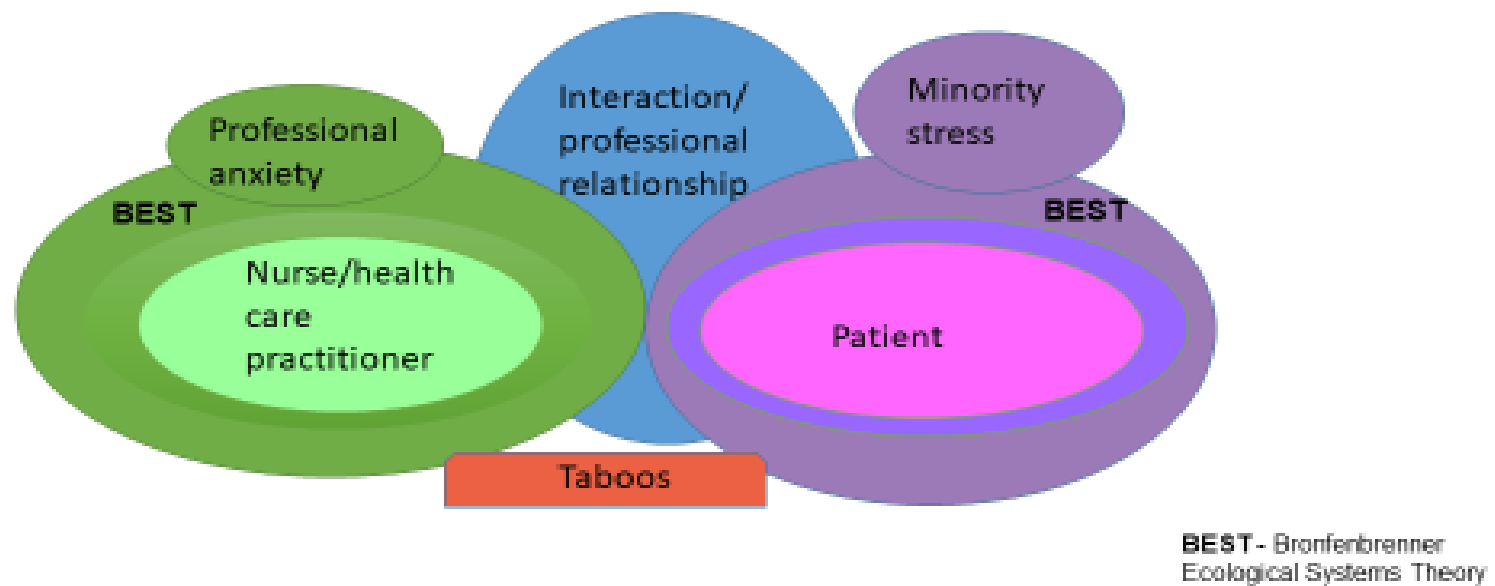


Figure 16 Conceptual framework following utilisation of education programme by health care professional (advanced level)

It is suggested that together with other interested staff, the specialist and link practitioners could develop a 'community of practice' in which research information and patient experiences and local information about resources, referral organisations and pathways can be brought together. In this way, they can enhance the quality of patient care.

Extract from reflective journal and reflexive comments:

"This phase of the study was rather difficult, as I needed to pull together all of the threads of the findings and look for exiting theories to explain these. It was clear quite early in the searching for theories that a single theory could explain the experiences of the women and healthcare professionals. The interaction / relationship between the two was seen as central and I needed to explain what influences this in regards to sexuality, sexual health and relationships in general and specifically in relation to patients from the LGBT community. I also needed to offer a model for improving practice in these areas - derived from the findings, a model which would be accessible to practitioners and implement in practice."

Reflexive comments:

- Checked potential influence of own past experiences in regards to focus group plan and schedule with my supervisors prior to ethics application and running the focus group.
- Scrutiny and justification by /with the ethics committee.
- Revisited existing literature - both sexuality in healthcare in general and cancer specific, to both inform the focus group schedule and also returned to during the analysis of the focus group transcripts.
- Constantly checking back with the data and analysis to confirm the framework was clearly derived from these.

In order to assess the accessibility and usefulness of the conceptual framework to cancer practitioners I need to return to the 'front line staff' to seek their views.

Chapter Ten: Journey Phase Four (B) – Presenting and discussing the conceptual framework with the cancer specialist nurses

Positionality – Reviewing application of the conceptual framework.

I learnt from the focus group with cancer specialist nurses that I was an ‘outsider’, perceived by the participants in many different ways, each carrying a particular set of assumptions. I was therefore keen to ‘set the scene’ for the focus group clearly, identifying who I was and what the intentions of the group were together with briefly outlining my personal, as well as professional interest and credentials. At the outset of the focus group, I made it very clear that although the study was mainly focussed on the needs of lesbian women the findings had shown that practitioners struggle with working effectively with **all** individuals in relation to the impact of cancer and treatments on their sexuality, sexual health and relationships. Thereby trying to make sure that the participants did not feel that I was coming from a position of personal bias.

To explore the conceptual framework in depth it was presented and discussed with a second group of 18 cancer specialist nurses undertaking the specialist cancer post registration programme at a UK University between 2016 - 2017 and opinion sought from the participants in the first focus group.

The aims of the focus group and short questionnaire were to:

- Gain the views and opinions of the participants of the conceptual framework and how this might fit with their practice.
- Ascertain the views of the proposed levels of practice resulting from the conceptual framework.
- With reference to the conceptual framework to seek the participant’s opinions about the content and format of any education /training programme or toolkit for developing their practice in the identified area of practice.

It was decided that the focus group would consist of two parts, a presentation and discussion of the conceptual framework and a short questionnaire to elicit the participant’s opinions on the contents of an education /training programme or toolkit to guide their practice.

The focus group discussion

The session commenced with an explanation of the background to the research study and a brief overview of the findings which had informed the construction of the conceptual framework. Written consent to participate in the study was then sort from and given from the participants. The group had previously been informed by their programme lead about the purpose of the study and asked to attend the focus group only if they were happy to take part in the study.

The session then proceeded to my presenting, outlining and explaining the conceptual framework including the arising levels of practice. From the outset I explained that although the study was exploring the impact of cancer and treatments ion the sexuality, sexual health and relationships of lesbian women (together with the reasons for focussing on these women) the implications for practice were far wider and included **all** women. On the whole the group understood the elements of the conceptual framework and were particularly interested in the concept of minority stress and the potential impact this would have on the nurse - patient interaction. Furthermore, they discussed quite happily the potential impact of the taboos around cancer, sex /sexuality and homosexuality. They did however express that they felt that society and practice had moved on recently in regards to same sex relationships. In this regards they said that they felt that they were able to treat all patients in the same way regardless of their sexual orientation. Clearly expressing heteronormative practice and finding it difficult to see that there might be dangers for the patients in adopting this approach.

On the whole the participant's agreed that their own background and life experiences, including professional ones could influence their therapeutic relationship with patients. Despite this, however, a number of the participant's expressed their unease with the notion of professional anxiety. Stating that they were all experienced practitioners and they didn't feel anxious when meeting their patients for the first time or in their continued work with them. Interesting, these feelings reflect those found by De Vocht (2011) in her study, where the practitioners were not able to 'own' their own unconscious incompetence (Benner, 2001). As many of the participants were very experienced practitioner's they found it difficult to recognise the 'mental checklist' they go through before any interaction with patients and /or significant others.

They did however discuss and agree that, as with the previous focus group, expert panel and the literature they felt far less comfortable and less confident when this was applied to working with patients in terms of the impact of cancer and treatments on their patient's sexuality, sexual health and relationships. Furthermore, as with the previous focus group and expert panel workshops the participants were unclear about the impact of these on their patients.

The group were then asked to look at the conceptual framework and discuss in groups what would be need to be included in an education programme and resources to develop the practitioner to move from level to level (within the framework). They were asked to consider this in terms of the knowledge, skills, attitudes and competencies needed and asked to complete the short questionnaire covering these. The participants found the exercise hard to complete, struggling mainly with the concept of the levels of practice equating these with the current nursing hierarchy and career progression pathways – which use similar terms especially advanced practice. However, following further discussion with the groups the participants had a clearer understanding of the conceptual framework and were able to identify the information requested.

Findings

The overall themes are presented in Table (31) below.

Practice level one (Basic)	Practice level two (Intermediate)	Practice level three (Advanced)
Information re: LGBT sexualities, lifestyles, relationships, sexualities. Sexuality (generally not LGBT specific).	Level 1 at greater depth/ enhanced skills .	Levels 1& 2 at greater depth/ advanced skills .
Communication, interpersonal & relationship building skills. Including LGBT terminology, appropriate language & creating a 'safe' environment. Use of scenarios and role play (for LGBT client scenarios).	Level 1 at greater depth/ enhanced skills (including discussing difficult subjects).	Levels 1& 2 at greater depth/ advanced skills .
Basic knowledge re: impact of cancer & treatments on sexuality : - Generally - LGBT specific	Level 1 at greater depth e.g use of vaginal dilators, effects of fistulas, sex after AP resection.	Levels 1& 2 at greater depth (expert knowledge).
Basic practical helping strategies – including how to approach the subject of sexuality c/o patients.	Level 1 at greater depth.	Levels 1& 2 at greater depth (expert knowledge).
Basic signposting to resources & help agencies.	Signposting to resources & help agencies.	Signposting to resources & help agencies (act as a resource for all staff).
Basic online training package (including case studies) – can be referred back to as a resource.	Level 1 at greater depth.	Level 2 at greater depth – formulation of support group terms of reference & programme.
	Facilitation skills for support group facilitation – to be inclusive of individuals from LGBT community.	Knowledge & skills of staff training /education.
		Understanding of culturally appropriate approaches & strategies for sexuality, psychosexual health across 'commonly encountered' cultures in practice.
		In depth online training package – can refer back to as a resource.

Table (31): Themes /Elements of education programme and resources

Interestingly, despite setting out the rationale for the focus of the study and the application to **all** women effected by cancer not just lesbian women, in the questionnaire one of the participants stated that they were

“Horried that this has been identified as an issue! Surely this is about better communication skills for healthcare professionals? Education /research should be focussed on sexuality in general not focussing on only 1 patient group!”

As this study has clearly shown there is such a need for the sexuality, sexual and relationships health to be assessed and addressed with **all** women effected by cancer and treatments, I can concur with the some of the feelings expressed. This study has also demonstrated there is a need, felt by both the lesbian women and other health care practitioners for more LGBT specific focussed education, practice and research.

Extract from reflective diary and reflexive comments:

“Because I knew from the previous focus group with the cancer specialist nurses that I was viewed as an ‘outsider’, I had thought through the best approaches to overcome this. As it was important, I needed the participants to feel comfortable enough to fully engage in the focus group discussion. This really ‘pulled’ on my skills and experiences of distressed and /or difficult clients, together with skills from my years of experience facilitating health care practitioner student groups.”

*“I found the focus group to be a useful process in that it on the whole confirmed the applicability of the conceptual framework to practice and practice development. In addition it extended the suggestions made previously by the initial focus group and expert panel for the content of education and practice development to address the gaps in their knowledge and skills in regards to the sexuality, sexual health and relationship needs of their lesbian patients. Also, the conceptual framework is aimed at all health care professionals, not just nurses. Therefore in light of the confusion experienced with the terminology regarding levels of practice, being conflated by the participant’s with the nursing hierarchy and career progression points it was **decided to re name the levels of practice to the basic, intermediate and substantive phases.**”*

“When I reflect on the difference between the two sets of healthcare practitioners i.e. expert panel and cancer specialist nurses and the degree of openness regarding the practitioners ability to address sexuality, sexual health and relationships with their patients. There are

clear differences, surprisingly the expert panel being more open about not knowing how to work with patients in these areas, the specialist cancer nurses being less open – until they felt safe enough with me to do so. Interesting - the expert panel are more my peers, so perhaps it was safer for them to be open with me, whilst the cancer nurses may have seen me as ‘threat’ – especially in potentially ‘uncovering’ weak areas in their practice.

Reflexive comments:

- Checked potential influence of own past experiences in regards to focus group plan and schedule with my supervisors prior to ethics application and running the focus group.
- Scrutiny and justification by /with the ethics committee.
- During the analysis of the transcripts adopted the phenomenological principles to try to ensure the voices of the participants were heard and represented (including ‘outlying’ experiences). As with the previous focus group, as a lesbian I had to be careful not to try to speak for the research participants who are on the whole, heterosexual.
- As previously and anticipated I felt like an ‘outsider’ with the focus group participants, possibly due to the impact of my non - researcher identity - this may have been perceived as ‘threatening’ by the participants, plus some may have seen me as ‘another academic nurse’ who is not in touch with day to day practice trying to ‘tell’ them how their practice should be.

Having constructed the conceptual framework and sought the opinions about its applicability with specialist nurses from across the major cancer centres in the region, the study can move onto wider dissemination of the findings and conceptual framework. As I had identified earlier my regrets about not previously making my work in the area of psychosexual health care made more widely known, I saw this dissemination as crucial. Also, I felt it was vital to maximise the potential for making the voices of the women heard in the wider healthcare arena in order to improve the quality of care provided for future patients and partners.

Chapter Eleven: Journey Phase Five – Journeys end or the end of the beginning? Critique, conclusions and recommendations

Having outlined the phases of the phenomenologically inspired journey this chapter reflects on, and concludes the journey undertaken. It provides a critique of the methods used together with some limitations, offers a personal reflection on the PhD journey, reviews the aims of the study and concludes with the recommendations from the study.

Critique and Limitations of the Study

This research journey began with women (including lesbians) attending breast cancer ‘moving forward’ programmes seeking help and support adapting to the impact the cancer and treatments had on their sexuality, sexual health (incorporating their psychosexual health) and relationships. Together with the healthcare professionals seeking information with regards to meeting the care needs of their Lesbian, Gay, Bisexual and Transgender (LGBT) patients concerning the impact of cancer on these areas of their lives. To that end the research journey needed to address the different groups of individuals, the patients, partners and healthcare practitioners. With a methodology found or developed which would ‘give voice’ to the experiences and concerns of all of these ‘groups’ of individuals. The methodology needed to be sufficiently flexible to facilitate the exploration of complex, multifaceted and sensitive aspects of life. In addition, the methodology needed to extend the existing knowledge base pertaining to the effects of cancer and treatments on individual sexuality, sexual health and relationships to include lesbian women and their partners. Together with develop a model for professional education and practice in order to improve the quality of the care provided to these women by the healthcare professionals involved in their cancer experience. The use of different research methods within the overarching phenomenological methodology successfully facilitated this. With the phenomenological principles and methods providing the rich description and the action research cycles (see Chapter Two) provided the ‘vehicle’ to develop and drive change in practice. The different data sets (Interviews, focus groups, expert panel and questionnaires) all had different purposes. The combination of these provided a more comprehensive picture of the ‘lived experiences’ and ‘world views’ of both the women effected by cancer and the healthcare professionals, these differing world views converging within the women’s cancer experience.

There are a number of limitations to the study. Namely, the small sample sizes limits its generalisability. Additionally, it was also limited to the lived experiences of lesbian women,

together with the views, attitudes and practice of healthcare practitioners related to this patient group. Therefore, ideally the study should be repeated with other LGBT 'groups'. With the conceptual framework being piloted with these and perhaps other minority or marginalised groups and adapted as necessary. This is seen as especially important as the concepts of sexuality and gender are recognised as becoming increasingly diverse and fluid.

Return to methodological rigour and positionality

From the outset of the research journey I recognised the need for myself as the researcher to make every effort to avoid or minimise bias throughout the study by various methods including modified bracketing and 'know yourself'. This commenced with my outlining my positionality at the outset and providing an ongoing commentary throughout on my positionality and methods for minimising my impact upon the study and managing potential bias. The criteria used to measure trustworthiness (Denzin & Lincoln, 2011, Englander, 2012) the following areas were carefully considered - credibility, dependability, transferability and confirmability. The study has given examples of the rich descriptions provided by the participants. During data analysis I constantly returned to the transcripts, questionnaires, field notes, reflective journal and original documents to minimise the influence of my judgement and safeguard against my 'interpretations' being a figment of my imagination. Thereby, drawing from **the essences** from the participants and not my bias. This was aided by the use of frequent debriefing and discussion with my supervisors throughout the research journey. Turning to authenticity, the criteria of fairness, ontological, educative, catalytic and tactical authenticity (Guba & Lincoln, 1989, Lincoln, Lynham & Guba, 2011) were also carefully considered. Fairness was addressed by checking and documenting that all the participants took part voluntarily and had sufficient time to reflect before completing documentation and questionnaires.

Ontological authenticity was achieved by the participants becoming more informed about the issues being addressed by the study. This is evidenced by the greater awareness of the focus group and workshop participants and the now ongoing work with the LGBT Cancer Alliance, Macmillan cancer support and local NHS Trust. Catalytic authenticity or action stimulated by the inquiry process is also evidenced by the above plus the actions of individual practitioners who attended the expert panel workshops, international cancer educator's conference (where I presented the study) together with co - organising and facilitating workshops at a regional LGBT and sexuality event - aimed at health and social care practitioners. These developments and initiatives, together with the participants developing an awareness and empathy for the conceptual framework also evidence educative authenticity.

Finally, tactical authenticity – the desire to undertake action via the understanding of the importance to change is also evidenced by the above demonstrating that a change in

professional education and practice is underway. In addition, as will be outlined in the conclusion section my work within a Macmillan Cancer Support /Relate project as the 'lead cancer counsellor' is also evidence of both educative and tactical authenticity.

The journeys end or just the beginning of a new adventure – Personal reflections on the PhD experience and journey

At the outset of the PhD journey I had a long held passion and belief in the necessity for the sexuality and sexual health needs of patients to be recognised as a core component in patient care. To that end I had spent many years as an educator of healthcare professionals in this area. In addition to developing and facilitating post - qualifying education programmes at a variety of academic levels, I had given numerous key note presentations, written articles and book chapters together with being a member of professional body special interest groups /committee's aimed at improving patient care in these areas. Furthermore, I was an established 'campaigner' locally for the recognition of lesbian health issues. Together with my qualifications and experience as a psychosexual and relationship therapist, I felt that I was well placed to undertake the study. With a previous research and supervision background I felt that I had insight into what the PhD journey would entail.

Nothing in my background and experience really prepared me for the complexity of roller coaster ride of the journey undertaken. During the process of the research various new skills have been developed, such as flexibility in thinking and problem solving - which was mainly required to overcome the difficulties with recruiting the lesbian women and partners. Furthermore, the process brought to the fore attributes such as personal resilience which I had previously failed to recognise that I possessed. It also highlighted the need for me to recognise that whilst LGBT rights and equality in lifestyle choices is present in the UK and many societies, same sex and relationships are still not 'comfortably' recognised and respected by **all** healthcare practitioners. This has led me to review my own tolerance of homophobic views and those holding them, allowing me to wish to continue the 'struggle' that I first engaged with back in the 1980's.

My skills as a nurse, educator, therapist and researcher allowed me to undertake a very challenging study. Other less experienced researchers, without the commensurate experience would have found the study impossible to undertake, as without the use of 'therapy based' skills they would not have been able to get the participants to feel safe enough to open up and be honest (both practitioners and the women affected by cancer). It is not a research journey to be undertaken lightly or by inexperienced researchers.

A final reflection:

At the conclusion of undertaking this study the subject became a personal one, when my partner underwent investigations for possible ovarian cancer. This led to an intermission from both my studies and my work with Macmillan /Relate as a counsellor. The journey of the women in the study became a reality for both my partner and myself. The experiences of uncertainty around the potential diagnosis and outcome and the fear these generated were tremendous. At times it felt as though we were living the lives of the women in the study, especially in terms of the impact on our relationship. In addition, being 'on the other side' of the practitioner - patient relationship was also a reflection of the experiences described by both the women and the practitioners in the study - we experienced first-hand the **heteronormative practice and lack of human touch** described. All of which, as a practitioner myself I found even more disturbing than I had previously done when listening to the women's stories within the study. In my eyes this really made the need for education and practice development even more crucial. A positive outcome from this more personal journey was experienced when I was able to return to the study and reviewed again the data from both the women effected by cancer and the healthcare practitioners. I was able to enter their world more fully, giving greater appreciation to what they were 'telling' me. One of the benefits of this was the recognition pertaining to the use of the language and terminology used by professionals and patients concerning the words intimate relationship and intimacy. It was recognised that this language may itself present a **barrier to clear communication** about the need for **closeness and comfort** (none sexual intimacy) experienced by the women in the study. It is suggested that the use by the practitioner of terms such as closeness and comfort may facilitate more openness to support by the women and partners. By, for example asking "how do you stay close to your partner". Whilst thankfully, all appears to be clear for my partner it has given me insight into the need for the provision of support from the healthcare professionals during the times of uncertainty in order acknowledge the fears and anxiety of both patients and partners experience.

Throughout the study I had utilised supervision as a means of addressing trustworthiness within the study, to minimise the influence of my judgement and safeguard against my 'interpretations' being skewed by my experience or views. This proved essential when returning to the study following my personal experience of being the partner of a lesbian woman effected by a potential cancer diagnosis.

This study was borne from the desire to make the voices of a marginalised group of women experiencing or having experienced a very vulnerable period in their lives (their 'journey'

through cancer) heard by healthcare professionals and the wider world. The interviews and online responses gave a rich description of the 'inner world' and 'world view', which at times was distressing to 'hear'. However, the study journey has proved invaluable in providing insight for healthcare practitioners into these women's lived experiences - especially so with the **unique insight** with regards to the partners of lesbian women effected by cancer. It is anticipated that through the dissemination and further development of the conceptual framework and the commensurate education programme /package future cancer care practitioners will be able to provide quality, sensitive and appropriate care for these women.

Conclusions

Aim one:

To explore the sexuality and sexual health (incorporating psychosexual health) and relationships experiences of lesbian and bisexual women who have been diagnosed and received treatment for cancer.

Following the expert panel workshop, questionnaire and documentary review and the growing need to identify how lesbian and bisexual women experienced their interactions with healthcare practitioners in regards to their sexuality, sexual health and relationships. This overarching study aim was broadened to include the following sub - aims:

- To explore the sexuality and sexual health experiences of lesbian and bisexual women who have been diagnosed and received treatment for reproductive and female cancer. Together with the experiences of their partners.
- To explore whether the women experienced any difficulties with their sexual and other relationships as a result of their cancer and its treatment. And where the women are in a couple relationship, to explore whether these impacted upon their experiences of sexual intimacy with their partner.
- To explore their experiences of healthcare practitioners in regards to their sexual orientation and the practitioner's willingness to assess and address any sexuality, sexual health (incorporating psychosexual health) and relationship issues related to their cancer.

Individual interviews and online questionnaires were used to undertake the exploration of the experiences of lesbian women effected by cancer and treatments in regards to their sexuality,

sexual health and relationships. Together with their experiences of healthcare staff in this regards. These provided an in depth insight into their 'world views' of these aspects of their cancer experience. As stated previously (page 84), although every effort was made to recruit bisexual women and their partners as participants in the study only lesbian women participated. This has obviously implications for the applicability of the conceptual framework to this group of women.

Having reviewed the existing available literature regarding the effect of cancer and treatments on lesbian women's sexuality, sexual health and relationships, it appears that this study is unique in exploring the effects of these on lesbian women in the UK, furthermore it is ground - breaking in exploring the impact on the partners of lesbian women effected by cancer. The experiences of these women will be discussed below. This study found that within a coupled relationship, both partners were found that the cancer experience altered and rocked their sexual intimacy and relationship (even on a transient basis).

The priority for the women, both survivors and partners throughout the treatment phase was survival, everything else was reported to be secondary. Sexuality (including sexual orientation) and sexual intimacy were not on their agendas. Furthermore, because of the many unwanted side effects of treatment the women with cancer did not feel able to be intimate with their partners. Nor did the partners want to be sexually intimate, whilst the person they loved was experiencing such a dreadful time. The partners did however describe missing the closeness that sexual intimacy brings. Many of the women described how they had pushed their partners away, through fear that they wanted to be intimate. This had led to partners feeling rejected and hurt, with the both the women and their partners feeling lost and lonely within their relationships. The women described their need for closeness and comfort throughout the cancer experience, which is seen as an important issue. As they appear to have equated intimacy only with sex, raising a point about the differences between language or terminology used by professionals and lay individuals. If the healthcare practitioner uses the terms intimacy or intimate relationships when assessing and addressing sexuality or relationship focussed care needs with patients they are 'closing the door' on a discussion of how the couples need for closeness and comfort will be met throughout their cancer experiences. As the women may not equate intimacy with closeness and comfort, and furthermore they would be see the terms as more appropriate. This needed to be addressed within the conceptual framework and model for an educational programme.

Both the survivors and partners identified that when sexual intimacy did resume, after the treatment period that this was done slowly, gradually with time being taken, with partners identifying that they were hesitant to touch through fear of hurting their loved one. Part of the

redevelopment of sexual intimacy was the need that both parties found to re-establish an adult partner relationship, moving back towards their pre-cancer relationship dynamic or establishing a new equality within the relationship. Within the re-establishment of a sexually intimate relationship the women found they needed to renegotiate the nature of this relationship. This renegotiation was made easier if the couple had managed to maintain non-sexual intimacy through the treatment period and were able to talk about their concerns, needs, desires and wishes. Unfortunately, for some women this wasn't possible leading to a non-resumption of their sexual and intimate relationship with their partner. Cancer having driven a wedge through their relationship that they and their partners were not able to breach.

Both the women and partners identified that their previous relationship dynamics and norms had been altered and in some cases severely compromised, both during and after the treatment period. The changes within their relationships were both in terms of the physical roles and the emotional interplay between the couple. Both the survivors and partners found that they struggled with the change in role from lover/partner to 'cared for' and 'carer' difficult to manage. Indeed, despite being women some of the partners found they struggled with the physical and intimate aspects of care - which was unexpected within a lesbian relationship, not conforming to the gender stereotype of women being 'naturally nurturing'.

One of the things which facilitated the rebalancing of the relationship was the couple's ability to maintain good couple communication throughout the illness and recovery times. Both the women and partners identified how the cancer experience had 'rocked' their relationship, causing them to argue and be in conflict with each other which both found frightening. A number of the partners identified how they avoided saying too much to their partner about trivial things, which they would have previously made a point of mentioning - through fear of causing more conflict. Furthermore, both the women and partners avoided having difficult conversations, leading to a collusion of silence and an increasing distance between the couple.

The women and some partners identified that this had actually led to a better post cancer relationship with their partners, as they had been able to successfully renegotiate their post cancer relationship roles. Unfortunately, however for some of the women in this study this wasn't possible and their cancer proved to be too much for their relationship to withstand, leading to breakdown of the relationship and separation.

Cancer and treatments challenged the women's sexuality in a number of ways. Changes in their body image, directly challenging the women's sense of attractiveness and femininity. Linked to this was the importance to them in their adaptation, of their partner's response to their altered body. One of the differences identified within this study was that some of the

women expressed their surprise at how important their body image was to them as lesbians. Many of the women identified that they did not feel attractive with the result that they couldn't see how their partners may do so and wish to be sexually intimate with them. The changes in body image and attractiveness contributed to the women experiencing an altered sense of self, together with a loss of their self and sexual identity, impacting on their self-confidence. As an altered body image had previously been identified within the heterosexual literature, it is suggested that these changes in body image and altered sense of self are likely to be experienced by all women who have undertaken the cancer 'journey'. What appears to be new is the identification of the shock experienced by the lesbian women that their altered body image should rock the foundations of their sense of self. It could be argued that this sense of shock is also present for some heterosexual women, which contributes to their overall difficulty adapting to their 'post cancer self'. Furthermore, the healthcare practitioners also identified that they felt underprepared to address the alterations in body image experienced by patients in their care. Therefore, there is a very clear need for professional education for healthcare staff in this area, consequently this needed to be addressed within the conceptual framework and model for an education programme.

All of the women experienced a changed view of the world and the formation of a 'new reality', whilst grieving for their pre - cancer lives. The women identified that they had experienced alterations in the sensations and sexual feelings, as a result of treatment and the treatment precipitated menopause. These had led to difficulties in both sexual desire and arousal - having a direct impact on their intimate relationships. For those women who were not in a current relationship these alterations, together with fear of rejection contributed to them being hesitant to form new relationships.

In terms of implications of the above to practice, it is seen as essential that healthcare and other practitioners (including counsellors) are aware of the impact of cancer and treatments has on both the sexual and non - sexual aspects of their patients' lives. This is crucial for them to be able to appropriately address these issues with their patients and partners, throughout their cancer experience.

Many of the women and partners expressed their fear of homophobia in their interactions with healthcare professionals. Happily, for the most part these fears were not borne out in reality, with most experiencing respectful, non - judgemental and inclusive care. Most of these women however described having experienced assumed heterosexuality in their care journeys. This raised the issue of heteronormative practice. With practitioners failing to recognise the importance of the specific aspects of lesbian women's lives which needed to be taken into account. Unfortunately, not all of the women experienced non - discriminatory care from the

healthcare practitioners involved in their care. Identifying that both the practitioners comfort with homosexuality and talking to patients about sexuality (generally) impeded their relationship with the practitioners, stifling their willingness to ask for help from the practitioners when they were experiencing difficulties in their sexual relationships. Some of the women, given their previous experiences of the healthcare system were distrusting of healthcare professionals, this is an aspect of the women's lives which the healthcare professionals need to understand and take account of when working with these women and their partners.

Whilst it is heartening to see that some progress has been made in terms of tackling homophobia in healthcare, it is also clear that the development of heteronormative practice is still impeding the development of individually focussed, holistic care for lesbian women and their partners. It is therefore essential that healthcare practitioners are empowered to deliver this patient focussed /centred care with their lesbian patients and partners through professional education and training. This should provide the practitioners with relevant, up to date knowledge of LGBT lifestyles, relationships, sexual behaviours and the impact on health of minority stress. Together with furnishing information regarding appropriate organisations and resources to which the practitioner could signpost the patients. Further it should develop the practitioner's skills to address sexuality, sexual and relationship health issues with all patients.

In terms of accessing support and information from the non - statutory cancer focussed organisations, either via helplines or attendance at survivor support groups, the women in this study found these to be very heterosexually focussed. The support groups attended being none 'gay friendly' and not safe places to be open and fully discuss their concerns and worries. In addition, the partners identified a lack of LGBT specific information or support being available for them from none statutory organisation helplines or websites. As with the healthcare staff above, it is seen as essential that staff from none statutory cancer support organisations are empowered to provide more personalised and inclusive information and support. Support which takes account of the diversity in lifestyles and relationships within the UK. Education and training are seen as crucial for these developments.

Both the women and partners identified that although the healthcare practitioners were technically and clinically competent, they often lacked the human skills and attributes needed to make them feel comfortable and part of the care partnership. Indeed, they identified a lack of basic communication skills being demonstrated by the healthcare and helpline staff. A lack of communication skills was also identified by the healthcare practitioners. Therefore, education and training to facilitate the use of basic communication skills is seen as essential

for both healthcare practitioners and 'patient facing' staff within both the NHS and none statutory cancer support organisations

Many of the women identified the loss of control they felt following the cancer diagnosis and throughout the treatment period. With the locus of control sitting with the healthcare team, and the survivors describing how they became the person to whom things happened and not feeling part of an adult to adult relationship. The journey was experienced like a roller coaster ride, an unpleasant one - with others in charge of the controls and guiding the direction of their lives. This feeling together with the sense of loss they identified occurred when the treatment has finished and the healthcare team and comradery with fellow patients disappear from their lives made the women feel vulnerable and 'all at sea'. These feelings are something which I commonly encounter in my counselling work with people effected by cancer, and are an issue which post cancer support and /or survivorship programmes need to make sure are addressed. As the trauma of the cancer experience doesn't end when the patient's treatment finishes.

Conclusions

Aim two:

- To develop a conceptual framework for practitioners working with lesbian and bisexual women in the fields of cancer care in regards to their sexuality, sexual health (incorporating psychosexual health) and relationships.

The data collected from the healthcare professionals, documentary review and the women (who had experienced cancer) and their partners, together with a review of existing research information and potential explanatory theories were all used to develop the conceptual framework. The conceptual framework was seen as the interplay between different, dynamic elements which come together within the interaction or professional relationship between practitioner and patient. As such the conceptual framework had to facilitate change in practitioners /professional practice. Figure (13) below outlines the proposed conceptual framework.

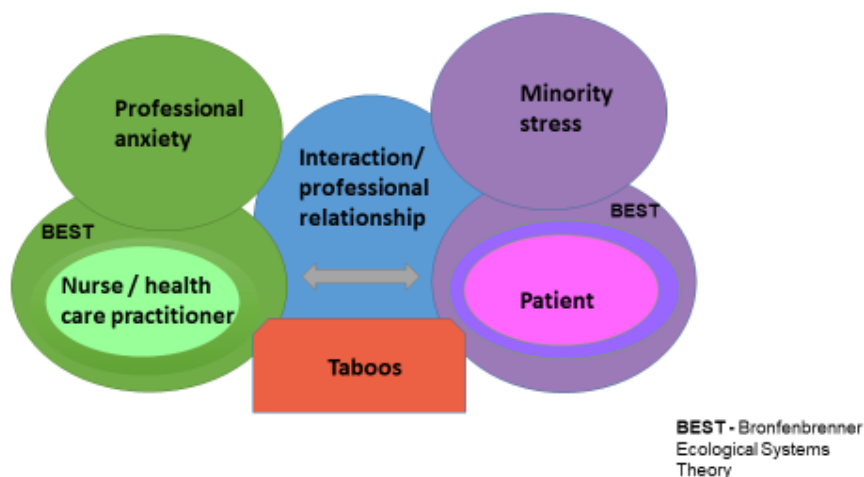


Figure (13) : The Conceptual Framework

At the heart of any conceptual framework for treatment or care planning with patients and their significant others, is the interpersonal relationship which develops or exists between them and the healthcare practitioners. Thus this relationship, together with skills and qualities required for its development and maintenance are central to the conceptual framework. When the patient or significant other and healthcare practitioner meet, they bring with them their own personal history of background, upbringing and life experiences - their individual ecological system. One of the crucial aspects when addressing an individual's sexuality and psychosexual health is the practitioner's level of comfort, and ability to self - assess their knowledge, skills and attitudes in relation to sex and sexuality - sexual self-awareness. Furthermore, when meeting the care needs of individuals from the LGBT community, the practitioner must be aware of their beliefs and attitudes towards same sex relationships and be willing to examine the potential impact of these on the practitioner - patient relationship and quality of care they provide. During the development of a professional, therapeutic relationship between the healthcare practitioner and the person affected by cancer, both parties bring with them a degree of stress or anxiety. Minority stress suggests that LGBT people experience an inherent stress due to society and services being geared towards and favouring those who are heterosexual or cisgender. It also involves the impact of the taboo's which have and to some extent still do exist regarding homosexuality and same sex relationships. They bring this anxiety with them to their interactions with healthcare practitioners and the healthcare system. Sometimes anticipating homophobia and confrontation. The responsibility for recognising the impact of minority stress together with anticipating the potential consequences for the patient, together with preventing negative practitioner behaviours, which can cause minority stress,

lies with the professional. It is, therefore, important that healthcare professionals and services are able to assure, or because of previous experiences, re-assure potential and actual patients that they will not be judged or encounter judgemental care. For this to be possible, the practitioners need to have sufficient targeted education about the LGBT lifestyles, relationships and specific aspects of care. Without this it would be difficult for them to feel comfortable and confident enough to provide respectful care. Indeed, the nurses in this study identified, that they do respect their LGBT patients, but they have insufficient expertise, so are anxious of how to 'do things right' not wanting to offend through ignorance. That is developing a sense of professional anxiety when working with patients in 'unknown' areas of practice.

Figure (17) below outlines the proposed model and content for an education programme for the development of healthcare practitioners.

Practice level one (Basic)	Practice level two (Intermediate)	Practice level three (Substantive)
Information re: LGBT sexualities, lifestyles, relationships, sexualities. Sexuality (generally not LGBT specific).	Level 1 at greater depth/ enhanced skills .	Levels 1 & 2 at greater depth/ advanced skills .
Communication, interpersonal & relationship building skills. Including LGBT terminology, general relationship terminology (including using closeness and comfort as terms instead of intimacy), appropriate language & creating a 'safe' environment. Use of scenarios and role play (for LGBT client scenarios).	Level 1 at greater depth/ enhanced skills (including discussing difficult subjects).	Levels 1 & 2 at greater depth/ advanced skills .
Basic knowledge re: impact of cancer & treatments on sexuality (including body image): - Generally - LGBT specific	Level 1 at greater depth e.g. use of vaginal dilators, effects of fistulas, sex after AP resection.	Levels 1 & 2 at greater depth (expert knowledge).
Basic practical helping strategies - including how to approach the subject of sexuality c/o patients.	Level 1 at greater depth.	Levels 1 & 2 at greater depth (expert knowledge).
Basic signposting to resources & help agencies.	Signposting to resources & help agencies.	Signposting to resources & help agencies (act as a resource for all staff).
Basic online training package (including case studies) – can be referred back to as a resource.	Level 1 at greater depth.	Level 2 at greater depth - formulation of support group terms of reference & programme.
	Facilitation skills for support group facilitation - to be inclusive of individuals from LGBT community.	Knowledge & skills of staff training/education.
		Understanding of culturally appropriate approaches & strategies for sexuality, psychosexual health across 'commonly encountered' cultures in practice.
		In depth online training package - can refer back to as a resource.

Figure (17): Model for an education programme and proposed content for the development of healthcare practitioners.

Developments And Personal Outcomes Arising From The Study

The PhD experience has facilitated my being able to present both the topic area and research findings to a new and wider audience, notably twice at the European Association for Cancer Education conference (see Appendices five and six) and at the American Association for Cancer Education (see Appendix eight). These experiences provided the opportunity for the lesbian women's voices to be heard by a wider audience of cancer practitioners and educators, which was seen as essential in beginning to change /improve practice in this often overlooked area.

The close working with the LGBT community required to undertake the study, led to a rekindling of my desire to 'campaign' with and for the community - something which had remained dormant for some years, due to other professional life pressures. From this working I became a committee member of the LGBT Cancer Alliance, which works nationally to address inequalities and promote equality in cancer care nationally. The LGBT Cancer Alliance brings together numerous key stakeholders from across the UK to work with them to promote LGBT sensitive care and establish cancer focussed LGBT health and wellbeing research and initiatives. One of the initiatives is around the provision of education and training with healthcare staff in regards to addressing the sexuality, sexual health and relationships of LGBT patients effected by cancer. It has been possible to feed into this ongoing initiative insights and information gained during the PhD journey, thus making the PhD 'live'.

In addition, the work with the LGBT Cancer Alliance has led to my working closely with and being part of the Macmillan Cancer Support LGBT taskforce, who are currently in the process of developing an education and training 'package' for cancer care practitioners pertaining to the LGBT patients sexuality, sexual health and relationships. Again, working as part of the taskforce has allowed the use and suggestions regarding 'appropriate' format and content stemming from my PhD experience to be utilised.

A further development from the PhD journey was being invited to co - organise, present and facilitate workshops at the first ever Macmillan Cancer Support LGBT conference for health and social care practitioners, held in May 2017. The conference was very well evaluated and there are plans to build on its success by continuing to work with health and social care providers to provide appropriate education and training for their staff. In addition, following the second focus group I was contacted by one of the participants who works for one of the major local NHS Trusts. As a result, I am working with the oncology practice educator to develop and run an education programme for the directorate nursing staff to develop the staff at the different levels proposed in the conceptual framework. In addition, I have been asked to join

a working party at the Institute of Psychosexual Medicine to create a training programme for doctors, nurses and other healthcare practitioners to develop their knowledge and skills when working with cancer patients in regards to their psychosexual and relationship health.

One of the unlooked for developments arising from the study was my own practice development within a joint Macmillan /Relate cancer support project took place at the time of my retirement from higher education work. It allowed me to actively re - engage with my counselling /therapy practice, within which the insights, knowledge and 'expertise' gained through undertaking the study have given me have been used extensively and directly with clients. In addition, the work has led to my development as 'cancer lead counsellor' for the project. As a result I have developed and provided education and training to health and social care practitioners for example hospice professionals and practice nurses, this is seen as a continuing policy and practice development.

Continued developments arising from the study since submission of the thesis

One of the underlying issues highlighted by this study, the effects of which could not be underestimated was the dehumanising processes experienced by the lesbian women and their partners whilst engaging with the healthcare professionals responsible for their treatment and care. The failure on the part of the healthcare professionals to recognise and address the women's individuality, adopting a 'one size fits all approach' allowed the professionals to focus only on the common elements of cancer and its treatment, and these tend to be physical and physiological, not psychological. It has to be a cause for concern that the shortfall in practice was not only experienced in terms of the women's sexuality, psychosexual health and relationships, but more generally in terms of the lack of human touch experienced. The perceived lack of caring and compassion encountered by the women at a very vulnerable time of their lives was unacceptable. The iteration of how this affected participants was distressing, leaving me as researcher and professional desperately seeking appropriate responses. As stated previously it was and is, essential that this issue be formally addressed in depth via the education programmes undertaken by health care professionals involved in care generally, and more specifically in cancer. To that end I felt that I had to continue the work undertaken post submission of the thesis prior to the viva voce. Thus, I remain an active member of the LGBT cancer alliance and Macmillan cancer support LGBT taskforce, developing LGBT sensitive and specific learning resources for health care professionals working within the cancer services. In addition I have agreed to continue consultancy work with Macmillan cancer support. I am now undertaking a review their current psychosexual and relationship documentation for patients, partners and healthcare practitioners including the LGBT specific content. An additional aspect of this

consultancy work stream is the review of training material and patient information booklets addressing the 'how to talk' elements of care. This includes developing materials to enhance the skills of professionals regarding how to have difficult discussions – one of the key skills found to be lacking in and by healthcare staff in this study. In addition, I am a member of the steering committee for the Institute of Psychosexual Medicine curriculum development, formulating a module pertaining to how to address the sexuality and psychosexual health needs of people effected by cancer (including LGBT specifics). This module is designed for both medical and nursing practitioners. Then too, I continue to work as the lead nurse counsellor for a Macmillan – Relate project that includes developing and delivering training and related resources based on the outcomes of this study.

Also, I have now been appointed by Breast Cancer Care to facilitate the breast cancer recovery/ support groups, working with 50% of the groups in North Wales. This role has afforded me the opportunity to directly influence and deliver Lesbian and Bisexual (LB) sensitive support groups, an area identified in this study as requiring urgent attention. Further to this I am working on a consultancy basis with Breast Cancer Care North West to facilitate groups for young women post breast cancer, in terms their sexuality, relationships and intimacy.

Having recently moved I am currently involved in planning strategies to liaise closely with Bangor and Wrexham Glyndwr Universities to develop student training programmes for both pre and post qualifying medical and nursing students. In addition, I am now planning the development and implementation of in- house LGBT specific, psychosexual and advanced communication skills training for the cancer services of the North Wales NHS Trusts.

Finally, although I was due to present this study to the European Association for cancer Educators (EACE) conference this year (2018) this was not possible for health reasons. I have however been invited by the organisations board to present and facilitate a 'how to' workshop at next year's conference.

Overall, the project has developed its own momentum with a wider circle of professionals making contact and requesting support. I had not foreseen that so many different activities would emerged, but this fits with the maximum the research should generate further research and professional activities. It is anticipated that through the above activities and further, as yet unidentified/ unseen avenues that I will continue to facilitate the provision of truly person centred holistic care, with humanness and compassion at its core. All the activities in which I am involved will be evaluated and are likely to lead to further studies, thus, the end of the study is not the end of the journey – it continues.

Conclusions

Aim three:

- Recommendations for policy, practice and professional education to enhance the quality of care and hence quality of life of this marginalised group.

Although this was a phenomenologically inspired study and as such not designed for generalisation, at the start of this study, nevertheless it was hoped that the data would identify some areas where recommendations for policy and practice could be made. In actuality, as the study progressed consensus from the findings became increasingly evident, and therefore, the following series of tentative recommendation for education and practice have been drawn from within the data sets.

Recommendations

The following key recommendations are made from the study. For clarity these will be differentiated.

Recommendation one:

For the Cancer practitioner's role there needs to be specific and targeted education and training which includes:

- General aspects of addressing their patient's sexuality and psychosexual health needs.
- Targeted education about the LGBT lifestyles, relationships and specific aspects of care. To facilitate practitioner to become comfortable and confident enough to provide none heteronormative and respectful care.
- The elements of an education programme /toolkit as shown in Figure (17) presented in the conclusion section form the basis of the above education programme for practitioner and practice development.
- The development of an online education update and resource package which healthcare practitioners can access - to be hosted by a national cancer organisation.

Recommendation two:

There needs to be development of specific practitioner expertise levels to address the patients and partner needs in regards to the impact on their sexuality, sexual health and relationships of cancer and treatments, via appropriate education, training and partnership working. This needs to differentiate between roles:

- The most basic level should be that all healthcare practitioners working in cancer care should possess the necessary knowledge, skills and attitudes to deliver non - judgmental and LGBT sensitive care to patients and partners who are affected by cancer and treatments. This being the case both generally and importantly in relation to the sexuality, psychosexual and relationship aspects of care.
- The development of a second level of practice (intermediate) should be for the link nurses /practitioners. These staff would have a greater depth of knowledge and increased skills in the area both the impact of cancer of sexuality, psychosexual health and relationships generally and related to LGBT specific elements of care. These link practitioners will also possess a greater degree of comfort with working the topic area and working with patients to meet their sexuality, psychosexual and relationship needs.
- There needs to be development of a level 3 (substantive) specialist practitioner in the area of cancer related sexuality, psychosexual and relationship health, both generally and addressing the specific needs of individuals from the LGBT community.
- There needs to be liaison between healthcare practitioners (at intermediate and substantive levels) and staff within the LGBT organisations to find out more about the services they offer, assess their 'preparedness' to work with patients with cancer and also to establish working links with particular staff. Such liaison provides the opportunity for the LGBT specific organisations and groups to 'get to know' the staff within statutory services, thereby fostering closer, more integrated working and lessening misconceptions between the two sections of society. This would also hopefully decrease the mistrust of health care staff, which may be felt by staff within the LGBT organisations.
- There needs to be recognition that as the therapeutic relationship is mutually constructed more education within the LGBT communities of the 'moving towards' a more open relationship with healthcare practitioners, rather than assume a negative or homophobic response. This could be achieved through greater co - working on health initiatives at both national level and locally to build more trusting relationship.

Recommendation three:

There needs to be inclusion of sexuality, sexual health and LGBT health awareness be included in pre and post qualifying medical and nurse education curriculums, this needs to recognise:

- A core component of pre-qualifying medical and nursing curricula should include the holistic impact of cancer and treatments on individual's sexuality, sexual health, relationships and body image.
- Professional post qualifying education for healthcare and other practitioners regarding the impact of cancer and treatments has on both the sexual and non-sexual aspects of their patients' lives.
- There needs to be development self - awareness and reflective practice generally and specifically in regards to sexuality, sexual health and LGBT awareness. This is needed in order to develop practitioners who are able to provide person centred and sensitive care (generally and LGBT specific).
- There needs to be inclusion of specific **LGBT health** issues (including the impact of minority stress on health and wellbeing), adopting a holistic or social model in all pre - qualifying medical and nursing curricula.

Recommendation four:

There needs to be inclusion within pre and post qualifying medical and nursing education curriculums of the skills needed to build an effective therapeutic relationship. For example, communication skills and development of compassionate care. Furthermore, that these need to become embedded into practitioners lifelong learning and professional revalidation.

Recommendation five:

There needs to be development of more LGBT sensitive and appropriate care and /information in non - statutory cancer support agencies.

- Staff from non- statutory cancer support organisations need to be provided with education and training to provide more personalised and LGBT inclusive information and support, including the use of basic counselling /communication skills.

- Organisations and staff providing support groups for women who have experienced cancer need to undertake training regarding strategies to make these groups more LGBT inclusive.
- There needs to be access to information regarding the LGBT specific signposting information and resources for support agency staff

Recommendation six:

There needs to be further research in this field to include:

- Participatory study to further develop the model of practice and educational 'toolkit'.
- Exploratory studies to assess the appropriateness of application of the conceptual framework to gay men, bisexual women and transgendered individuals

Dissemination

The first round of dissemination of the study is it will to be shared via the project website with the women who wished their voices to be heard and to count, together with feeding these back to the healthcare practitioners who kindly participated in the journey with me. It will also provide feedback to those LGBT organisation who kindly helped with the study by providing links to potential participants and also functioned as 'critical friends' throughout the study.

In addition to the practice developments arising from this study, it is planned to begin the process of wider dissemination academic and practice at an appropriate European Association for Cancer Education conference in 2019. Furthermore, as requested by the conference organisers, it is intended to present the study findings at the International Cancer Education Conference, which is attended by practitioners, educators and patients in the USA in 2019. Dissemination via this conference will afford the opportunity to potentially influence national policy in the USA as the conference is attended by national policy makers. Furthermore, as the educators from the Cancer Patient Education Network are practitioners whose primary role is patient education it provides the opportunity to create awareness of the issues for lesbian women prior to them accessing formal healthcare. Finally, the study will be disseminated via practice academic journals such as The Journal of Cancer Education and Journal Sexual and Relationship Therapy.

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Appendices

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Appendix 8	International Cancer Education Conference presentation - 2014

Appendix 1: Ethical Approval letter: 23.10.2014

Address for Correspondence

Dr James Williams
Attwood Building
Birmingham City University
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Tel: 0121 331 6673

Email: james.williams@bcu.ac.uk



23rd October 2014

Joy Hall
Faculty of Health, Education and Life Sciences.
Birmingham City University
Seacole Building
Westbourne Road
Edgbaston
Birmingham B15 3TN

Dear Joy

Re: An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for reproductive and female cancer.

Thank you for your application and which was reviewed by the Faculty Research Ethics Committee on Monday 20th October 2014. Thank you also for joining the meeting; it was very helpful to be able to clarify a number of issues face to face.

The Committee is happy to issue a favourable opinion. This means that you may begin the project.

This opinion is based on the information supplied in the documents dated XX. If you wish to make any substantial changes to the research please contact the Committee and provide details of what you propose to alter. A substantial change is one that is likely to affect the

- safety and well-being of the participants;
- scientific value of the study;
- conduct or management of the study.

The Committee should also be notified of any serious adverse effects arising as a result of the research.

The Committee is required to keep a favourable opinion under review in the light of progress reports. You will be asked to submit a progress report and the Health Research office will contact you when this is due.

Faculty of Health
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Appendix 2: Ethical Approval letter: 24.3.2015

Ref: JW/jb 098/2014

Tuesday, 24 March 2015



Tel: 0121 331 6673
Email: james.willias@bcu.ac.uk

Joy Hall
Seacole Building

Dear Joy Hall

Re: An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for reproductive and female cancer.

Thank you for informing the Faculty Research Ethics Committee of proposed changes to the methodology of the above study. The changes, as you informed me in an e-mail of Monday 19th January 2015, involve 'widening the media for recruitment to include the use of facebook and other online sources utilised by the LGBT organisations and their partner organisations locally and nationally.'

The Committee is happy to approve the changes. We will, of course, require written confirmation that the organisations are happy for you to proceed in this way. Please forward such relevant correspondence to me as soon as you can.

I hope the project goes well and wish you every success.

Yours sincerely,

Dr James Williams

Deputy Chair, Faculty of Health, Education and Life Sciences Ethics Committee

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Appendix 3: Ethical Approval letter: 17.6.2015

Ref: JW/jb 098/2014

Wednesday, 17 June 2015



Email: HELS_Ethics@bcu.ac.uk

Joy Hall
Seacole 457

Dear Joy Hall

Re: An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for reproductive and female cancer.

Thank you for informing the Faculty Research Ethics Committee of proposed changes to the methodology of the above study. The changes, as you informed me in an e-mail of Monday 29th May 2015, involve the following:

1. In order to undertake documentary of undergraduate nursing and medical curriculum documents – approval to request the documents from UK Universities with said education provision.
2. Addition of facilitated focus group discussions with SMW and/or partners via the LGBT organisations previously approved. These will be in addition to the individual interviews previously approved.
3. Advertising in the LGBT press e.g. *Pink News* (online).

The Committee is happy to approve these changes.

I hope the project goes well and wish you every success.

Yours sincerely,

James Williams
Deputy Chair, Faculty of Health, Education and Life Sciences Ethics Committee

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Appendix 4: Ethical Approval letter: 2.3.2016



Ref: MH/98/2016

Address for Correspondence

Faculty of Health, Education and Life Science Research Office
Faculty of Health, Education and Life Sciences
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2nd March 2016

Joy Hall

Faculty of Health, Education and Life Sciences.
Birmingham City University
Seacole Building
Westbourne Road
Edgbaston
Birmingham B15 3TN

Dear Joy

Re: An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for reproductive and female cancer.

Thank you for informing the Faculty Academic Ethics Committee of your proposed changes and documentation regarding the above study. The changes, as you informed me in an e-mail 1st March 2016, involve the following:

- The use of online questionnaires for both the lesbian & bisexual women who have had cancer and the partners. This will be facilitated by the use of the Bristol online survey.
- The use of a project website which will contain all of the project information e.g. participant information, consent forms and contact details. This will also have a link to the questionnaires. Access to the contents of the website will be confined to you. The website information and link will be circulated via the LGBT participating groups networking / news media, together with the website being generally open to internet users.
- The findings of the study (including those from the questionnaires) will be made available to participants via the website. The website will closed after the completion and full dissemination of the study.
- The use of both Skype and email interviewing to promote participation of women in less accessible areas (Skype) and to reduce the potential discomfort when speaking face to face about very personal issues (email).

I am happy to approve these changes.

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Appendix 5: Expert panel workshop abstract – Poland



Authors:

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Workshop

Sexuality and sexual health concerns of lesbian and bisexual women and their partners following diagnosis and treatment for female and reproductive cancers

The past couple of decades has seen an increased interest in, and awareness of the ways in which cancer and concomitant treatments effects individuals and couples expressions of sexuality and their sexual health (Sadovsky & Bassoon et al, 2010, Greenwald & McCorkle, 2008; De Vocht 2011).

In addition, mainly due to changes in societal perceptions of sexual diversity, the health care needs of individuals from sexual minority groups has begun to be recognised and addressed by practitioners (Stonewall, 2010). There is literature both reporting research studies and reviewing the available evidence around the potential increased risks of lesbian and bisexual women to some cancers (including female and reproductive cancers) (Brandenberg & Mathews, et al, 2007, Zaritsky & Dibble, 2010).

However, when exploring the current evidence with regards to the sexuality and sexual health needs of these individuals there appears to be a dearth in available literature to help guide practice in this area. This interactive workshop will present a critical review of the current evidence base available to guide practice in this area, in addition it will ask the participants to identify and explore the following:

- Attitudes of nurses and health care professionals towards lesbian and bisexual patients
- Appropriateness of cancer services for lesbian and bisexual women
- Assessment and interventions with lesbian and bisexual women and their partners in regards to their sexuality and sexual health

Finally, the workshop will outline recommendations for future research in the area of sexuality and sexual health in lesbian and bisexual women and their partners following diagnosis and treatment for female or reproductive cancer.

Abstract 20

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Appendix 6: Expert panel workshop abstract – UK



Authors:

Joy Hall
Associate Professor/Head of
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Birmingham. B15 3TN

Workshop 3:

Sexuality and sexual health concerns of lesbian and bisexual women & their partners following treatment for cancer: Patient and Educators experiences and views

Background

Over the past couple of decades numerous studies have shown that cancer and its treatments have an impact upon individuals and couples expressions of sexuality and sexual health, mainly focussed on the experiences of heterosexual women. Very limited studies have explored the experiences of lesbian and bisexual women, therefore there is an apparent dearth in available literature to help guide practice in this area. Additionally, although the health care needs of individuals from sexual minority groups has begun to be recognised and addressed by practitioners, the question remained as how prepared practitioners are to address the psychosexual and relationship needs of these patients.

Aim

The focus of the project is to explore the sexuality, sexual health and intimate relationship experiences of lesbian and bisexual women and their partners following treatment for cancer. Together with exploring the attitudes and preparation of health care professionals working in the cancer field when encountering these women in practice. The ultimate aim is the development of an educational toolkit to guide health care professionals to provide culturally sensitive care in these areas.

Methods

Adopting a modified action research model, the project, to date has utilised the following:

- Survey of expert cancer practitioners and educationalists.
- Focus group interview with cancer specialist nurses
- Documentary analysis of U.K undergraduate/ pre- qualifying medical and nursing curricula.
- Documentary analysis of U.K. policy documents and practice documents relevant to both sexuality/sexual health and LGBT health related issues.
- Semi structured interviews of lesbian and bisexual women who have been treated for primary cancer.

Findings


The survey demonstrated that overall the practitioners did not ask patients and did not feel comfortable asking about sexuality, sexual health or intimate relationships in general and even less comfortable in addressing these with sexual minority patients. The focus group showed that whilst the practitioners are willing to address these areas with patients, they feel ill prepared to do so, being even more so when working with sexual minority patients. This is not surprising given the findings from the documentary analysis with little curriculum content related to both sexuality issues and sexual minority health. The experiences of the women (to date) echo the above together with fear of potential discrimination should they disclose their sexual orientation to their health care providers.

Abstract 23

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Appendix 7: Example recruitment information, interview schedule and online questionnaires - Lesbian and bisexual women affected by cancer

Appendix 7 (a): Recruitment leaflet – Lesbian and bisexual women with cancer

 <p><i>I am undertaking a study exploring the relationship (including sexual relationship) experiences of lesbian & bisexual women who have been diagnosed and received treatment for cancer. As part of the study I am wanting to interview women who are willing to share their experiences of these areas with me.</i></p> <p>Why am I doing the study? <i>The ultimate aim of this work is to help guide and develop health care practice when working with lesbian and bisexual women and their partners, affected by cancer.</i></p>	<p>What will taking part involve? <i>If you agree to participate you will be asked to take part in a one hour individual interview, which will take place at the Birmingham LGBT Health & Wellbeing Centre (Holloway, Birmingham) or another venue which is convenient for you. Travel expenses will be reimbursed.</i></p> <p>Who is responsible for the study? <i>My name is Joy Hall, I am Head of Department Public & Community Health at Birmingham City University (Faculty of Health). I have a long standing professional interest in relationships & sexuality in health care, and am a qualified nurse, educator and psychosexual & relationship therapist.</i></p> <p>What should you do if you want more information about the study or are interested in helping with the study? Contact myself : Joy Hall : email: joy.hall@bcu.ac.uk</p>  <p>BIRMINGHAM CITY University</p>	<hr/> <p><i>Calling all lesbian & bisexual women!</i></p> <hr/>  <ul style="list-style-type: none"> • <i>Have you ever had cancer?</i> • <i>Would you be willing to help with a small research study?</i> • <i>If so, please read on.</i>
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Appendix 7 (b): Participant information sheet – Lesbian and bisexual women affected by cancer (survivors)



Participant Information Sheet (version 2 date: 24.11.15)

Title of study:

An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for cancer.

Researcher: Joy Hall

Thank you for taking the time to consider volunteering to take part in my research study. This will involve you participating in an individual interview about your experiences. Before you decide whether you would like to take part, it is important that you understand what the research is about and what taking part will involve. Please take the time to read the following information carefully.

What is the purpose of the research?

This study forms the basis for my PhD related to the topic area. The ultimate aim of this work is to help guide and develop practice when working with lesbian and bisexual women and their partners, affected by cancer.

Why have I been chosen?

You have been chosen as you have experienced receiving the diagnosis and treatment of cancer. As such you are in the ideal position to provide insight into how (if at all) your illness and its treatments effected your sexual and intimate relationship with your partner/s. This is seen as important as it has been identified in the literature that this is an area of practice which is frequently overlooked, and as such little information is available to health care professionals working within the cancer services about these topics and how to approach the topic with lesbian or bisexual clients.

Do I have to take part?

You do not have to take part if you do not want to, if you decide to take part and then change your mind you are free to withdraw from the study at any point, without any questions being asked.

What will taking part involve?

If you agree to participate you will be asked to take part in a one hour individual interview, which will take place at the Birmingham LGBT Health & Wellbeing Centre Holloway, Birmingham) or a venue of your choice. The interview will be audio recorded and the contents will be typed up by the researcher. The interview will be analysed and the results feedback to you by post or email (should you wish) on completion of the study.

What are the advantages of taking part?

Although you may not benefit personally from taking part, the information will be used help inform health professionals about your experiences, to help shape the care and support they can provide to women such as yourself in the future.

What are the disadvantages of taking part?

Thinking about sexuality and sexual health may cause you some anxiety, if this is the case then you may decide not to take part in the study. Supportive counselling will be provided if needed.

If you choose not to take part, this will not affect your relationship with voluntary group of which you are member, indeed the group will not be made aware of your potential participation.

Will information the interview be kept confidential?

Yes, the information you provide will be kept confidential. The interview will not ask you for personal identifying details. These will be anonymised and held in a secure place. In the publication of the study it will not be possible to identify you as a participant.

Who has reviewed and approved the research?

This research has been insured by Birmingham City University. The Faculty of Health, Education & Life Sciences Research Ethics Committee has reviewed and approved it.

What will happen to the results of the research study?

The results of the study will be presented to the wider health care community via conference presentations and journal articles in professional journals.

The information you provide through your interview will also form the basis for the development of a training 'toolkit' for healthcare staff working in the area of cancer care.

Where can I get more information?

If you would like any further information about the research at any point or have any questions about the questionnaire , then please contact Joy Hall (project researcher) on her office number : 0121 331 6049 or email : joy.hall@bcu.ac.uk

Joy Hall (Researcher)
Faculty of Health, Education and Life Sciences
Birmingham City University
City South Campus
Birmingham B15 3TN

Thank you very much and I look forward to meeting you if you decide to take part.

As this is part of a PhD study you may wish to contact my research supervisor Professor Joy Notter

Birmingham City University
City South Campus
Telephone number 0121 331 6161

Should you wish to make a complaint about the conduct of the interview please contact:

Professor Lucy Land
Birmingham City University
City South Campus
Birmingham B15 3TN
Telephone number: 0121 331 6196

Appendix 7 (c): Participant information sheet – Lesbian and bisexual women affected by cancer (partners)



Participant Information Sheet - Partner (version 2 date: 24.11.15)

Title of study:

An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for cancer.

Researcher: Joy Hall

Thank you for taking the time to consider volunteering to take part in my research study. This will involve you participating in an individual interview about your experiences. Before you decide whether you would like to take part, it is important that you understand what the research is about and what taking part will involve. Please take the time to read the following information carefully.

What is the purpose of the research?

This study forms the basis for my PhD related to the topic area. The ultimate aim of this work is to help guide and develop practice when working with lesbian and bisexual women and their partners, affected by cancer.

Why have I been chosen?

You have been chosen as you have experienced your partner or previous partner receiving the diagnosis and treatment of cancer. As such you are in the ideal position to provide insight into how (if at all) their illness and its treatments effected your sexual and intimate relationship with your partner. This is seen as important as it has been identified in the literature that this is an area of practice which is frequently overlooked, and as such little information is available to health care professionals working within the cancer services about these topics and how to approach the topic with lesbian or bisexual clients.

Do I have to take part?

You do not have to take part if you do not want to, if you decide to take part and then change your mind you are free to withdraw from the study at any point, without any questions being asked.

What will taking part involve?

If you agree to participate you will be asked to take part in a one hour individual interview, which will take place at the Birmingham LGBT Health & Wellbeing Centre

Holloway, Birmingham) or a venue of your choice. The interview will be audio recorded and the contents will be typed up by the researcher. The interview will be analysed and the results feedback to you by post or email (should you wish) on completion of the study.

What are the advantages of taking part?

Although you may not benefit personally from taking part, the information will be used help inform health professionals about your experiences, to help shape the care and support they can provide to women such as yourself in the future.

What are the disadvantages of taking part?

Thinking about sexuality and sexual health may cause you some anxiety, if this is the case then you may decide not to take part in the study. Supportive counselling will be provided if needed.

If you choose not to take part, this will not affect your relationship with voluntary group of which you are member, indeed the group will not be made aware of your potential participation.

Will information the interview be kept confidential?

Yes, the information you provide will be kept confidential. The interview will not ask you for personal identifying details. These will be anonymised and held in a secure place. In the publication of the study it will not be possible to identify you as a participant.

Who has reviewed and approved the research?

This research has been insured by Birmingham City University. The Faculty of Health, Education & Life Sciences Research Ethics Committee has reviewed and approved it.

What will happen to the results of the research study?

The results of the study will be presented to the wider health care community via conference presentations and journal articles in professional journals.

The information you provide through your interview will also form the basis for the development of a training 'toolkit' for healthcare staff working in the area of cancer care.

Where can I get more information?

If you would like any further information about the research at any point or have any questions about the questionnaire , then please contact Joy Hall (project researcher) on her office number : 0121 331 6049 or email : joy.hall@bcu.ac.uk

Joy Hall (Researcher)

Faculty of Health, Education and Life Sciences

Birmingham City University

City South Campus

Birmingham B15 3TN

Thank you very much and I look forward to meeting you if you decide to take part.

As this is part of a PhD study you may wish to contact my research supervisor Professor Joy Notter

Birmingham City University

City South Campus

Telephone number 0121 331 6161

Should you wish to make a complaint about the conduct of the interview please contact:

Professor Lucy Land

Birmingham City University

City South Campus

Birmingham B15 3TN

Telephone number: 0121 331 6196

**Appendix 7(d) Consent form – Lesbian and bisexual women affected by cancer
(Survivors and partners)**



CONSENT FORM

Title of Project:

An exploration of the sexuality and sexual health experiences of lesbian & bisexual women who have been diagnosed and received treatment for cancer.

Name of Researcher: Joy Hall

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 24.11.15 (version 2) for the above 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 legal rights being affected. ☐
3. I agree to take part in the above study. ☐

<hr/>	<hr/>	<hr/>
Name of Participant	Date	Signature

<hr/>	<hr/>	<hr/>
Name of Person Taking Consent.	Date	Signature

Appendix 7 (e): Interview schedule – Lesbian and bisexual women affected by cancer (Survivor)

Interview Schedule (Survivor)

Introduction:

- Of myself as researcher, professional background.
- Reasons for undertaking the study & what is hoped it will achieve (refer to participant information sheet).
- Confirm arrangements c/o confidentiality & anonymity
- Confirm arrangements for post interview support (if required)
- Confirm arrangements for 'member checking' and project report
- Confirm arrangements for payment of travel expenses.
- Introduce the interview procedure.

Areas to be explored

- What type of cancer did you receive treatment for? And what type of treatment/s did you receive?
- How long ago was this?
- At the time were you in a relationship? If so, how long were you in the relationship at the time of diagnosis and treatment for your cancer?
- As you know I am interested to explore with you how your cancer & its treatment effected how you saw yourself sexually & how this (if indeed it did) effected your sexual/ intimate relationship with your partner. Perhaps you could tell me the story of your cancer journey in these areas please.
- If you were not in a relationship at the time of your cancer, have you subsequently been in a relationship? If so, for how long? Has your history of cancer effect your sexual and intimate relationship with new partners? If so, in what way/s?
- Are there any other issues related to the subject you want to discuss?
- **Thank you** for your time and honesty, I really appreciate that it may not have been easy to discuss such personal areas with me and I am most grateful for your willingness to do so.

Prompts:

- How did the diagnosis impact on your sense of 'self'? i.e. How you saw yourself?
- How did your illness effect the way in which you were able to 'perform' your normal role/s within your relationship?

- Many people who have cancer & are treated for it find that they experience difficulties with their sexual relationship/s – is this something you experienced & if so in what ways?
- If you experienced difficulties/ alterations in your sexual relationship how did you try to overcome these? What things did you find helpful?
- If you weren't in a relationship, how did your history of cancer impact on your 'willingness' to engage in a new relationship?
- Did you ever discuss the difficulties with any of the health care professionals dealing with you? If so, how helpful did you find it? If not, what prevented you doing so?

Appendix 7 (f): Interview schedule – Lesbian and bisexual women affected by cancer (Partner)

Interview Schedule (Partner)

Introduction:

- Of myself as researcher, professional background.
- Reasons for undertaking the study & what is hoped it will achieve (refer to participant information sheet).
- Confirm arrangements c/o confidentiality & anonymity
- Confirm arrangements for post interview support (if required)
- Confirm arrangements for 'member checking' and project report
- Confirm arrangements for payment of travel expenses.
- Introduce the interview procedure.

Areas to be explored

- What type of cancer did your partner receive treatment for? And what type of treatment/s did they receive?
- How long ago was this?
- How long were you in the relationship at the time of diagnosis and treatment for your partner's cancer?
- As you know I am interested to explore with you how your partner's cancer & its treatment effected your relationship both sexually & generally (if indeed it did).
- How the cancer and treatments effected your sexual/ intimate relationship with your partner. Perhaps you could tell me the story of your cancer journey in these areas please.
- Are there any other issues related to the subject you want to discuss?
- **Thank you** for your time and honesty, I really appreciate that it may not have been easy to discuss such personal areas with me and I am most grateful for your willingness to do so.

Prompts:

- How did the diagnosis impact on your sense of 'self'? I.e. how you saw yourself?

- How did your partner's illness effect the way in which you were able to fulfil your normal role/s within your relationship?
- Many people who have cancer & are treated for it find that they experience difficulties with their sexual relationship/s – is this something you experienced & if so in what ways?
- If you experienced difficulties/ alterations in your sexual relationship how did you try to overcome these? What things did you find helpful?
- Did you ever discuss the difficulties with any of the health care professionals dealing with you? If so, how helpful did you find it? If not, what prevented you doing so?

Appendix 7(g): Online questionnaire - Lesbian and bisexual women affected by cancer (Survivor)



Study Title:

An exploration of the sexuality and sexual health experiences of lesbian and bisexual women who have been diagnosed and received treatment for cancer.

Survivor questionnaire

Introduction to the questionnaire:

Thank you for taking part in this research study, which will involve you completing this questionnaire about your experiences on your 'cancer journey'. You are in the ideal position to provide insight into how (if at all) your illness and its treatments affected your intimate & sexual relationship with your partner/s.

This is seen as important as it has been identified in the literature that this is an area of practice which is frequently overlooked, and as such, little information is available to health care professionals working within the cancer services about these topics and how to approach the topic with lesbian or bisexual clients. The information that you give will be anonymised, and used to develop information packs for professionals and other women.

Questions:

1. What type of cancer were you diagnosed with and receive treatment for? Please tick:

Breast cancer	<input type="checkbox"/>
Cervical cancer	<input type="checkbox"/>

Uterine (womb) cancer	
Ovarian cancer	
Lung cancer	
Bowel cancer	
Other – please give specify which.	

2. What type of treatment/s did you receive?

Surgery – please specify type	
Radiotherapy	
Chemotherapy	
Other – please specify which	
Are you still receiving treatment/ taking medication? If so, what? Please specify	

3. How long ago was this?

6 – 12 months ago	
13 months to 2 years	
Longer than 2 years ago	

4. At the time were you in a relationship?

Yes	
No	

If **yes** please answer the following questions

If **no** please go to **question 6**

5. How long were you in the relationship at the time of diagnosis and treatment for your cancer?

Less than 6 months	
6 – 12 months	
13 months to 2 years	
Between 2 and - 10 years	
Longer than 10 years	

5a) Many people who have cancer & are treated for it find that they experience difficulties with their intimate and sexual relationships with their partners – is this something you experienced & if so in what ways? (free text)

5b) How did the diagnosis impact on your sense of 'self'? i.e. How you saw yourself? (free text)

5c) How did your illness affect the way in which you were able to fulfil your normal role/s within your relationship? (free text)

Now please go to question 11

6. If you were not in a relationship at the time of your cancer, have you subsequently been in a relationship? Please tick one box below.

Yes	
No	

7. If so, for how long?

Less than 6 months	
7 – 12 months	
13 months to 2 years	
Between 2 - 10 years	
Longer than 10 years	

8. If you have been involved in any new intimate relationships, has your history of cancer affected your sexual and intimate relationship with new partners? If so, please outline in what way/s? (free text)

9. If you experienced difficulties/ alterations in your new sexual relationship how did you try to overcome these? What things did you find helpful? (free text)

10. If you weren't in a relationship, did your history of cancer impact on your 'willingness' to engage in a new relationship? Please tick one box below.

Yes	
No	

Now please go to question 12

11. If you experienced difficulties/ alterations in your sexual relationship how did you try to overcome these? What things did you find helpful? (free text)

12. Did you ever discuss the difficulties with any of the health care professionals dealing with you? If so, how helpful did you find it? If not, what prevented you doing so? (free text)

13. Are there any other issues related to the subject you want to tell us about?

Thank you for your time and honesty,

Appendix 7 (h): Online questionnaire - Lesbian and bisexual women affected by cancer (Partner)



Study Title:

An exploration of the sexuality and sexual health experiences of lesbian and bisexual women who have been diagnosed and received treatment for cancer.

Partner questionnaire

Introduction to the questionnaire:

Thank you for taking part in this research study, which will involve you completing this questionnaire about your experiences on your 'cancer journey' with your partner. You are in the ideal position to provide insight into how (if at all) your illness and its treatments affected your intimate and sexual relationship with your partner.

This is seen as important as it has been identified in the literature that this is an area of practice which is frequently overlooked, and as such, little information is available to health care professionals working within the cancer services about these topics and how to approach the topic with lesbian or bisexual clients. The information that you give will be anonymised, and used to develop information packs for professionals and other women.

Questions:

6. What type of cancer did your partner receive treatment for? And what type of treatment/s did you receive? Please tick:

Breast cancer	
Cervical cancer	
Uterine (womb) cancer	
Ovarian cancer	
Lung cancer	
Bowel cancer	
Other – please give specify which.	

7. What type of treatment/s did they receive?

Surgery – please specify type	
Radiotherapy	
Chemotherapy	
Other – please specify which	
Are they still receiving treatment/ taking medication? If so, what? Please specify	

8. How long ago was this?

6 – 12 months ago	
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13 months to 2 years	
Longer than 2 years ago	

9. How long were you in the relationship at the time of diagnosis and treatment for your partner's cancer?

Less than 6 months	
6 – 12 months	
13 months to 2 years	
Between 2 and - 10 years	
Longer than 10 years	

As you know I am interested to explore with you how your partner's cancer and its treatment affected you and your relationship (both generally and your intimate/sexual relationship) with your partner. Please answer the following questions.

- 5a) Please describe how your partners illness affected your relationship in general (free text)

- 5b) Many people who have cancer and are treated for it find that they experience difficulties with their sexual relationship/s – is this something you and your partner experienced and if so in what ways? (Free text)

- 5c) How did the diagnosis impact on your sense of 'self'? I.e. how you saw yourself? (free text)

- 5d) How did your partner's illness effect the way in which you were able to fulfil your normal role/s within your relationship? (free text)

14. If you experienced difficulties/ alterations in your sexual relationship how did you try to overcome these? What things did you find helpful? (free text)

15. Did you ever discuss the difficulties with any of the health care professionals dealing with you? If so, how helpful did you find it? If not, what prevented you doing so? (free text)

16. Are there any other issues related to the subject you want to tell us about?

Thank you for your time and honesty,

Appendix 8:

International Cancer Education Conference presentation - 2014



International Cancer Education Conference

Building Global Bridges, Providing Quality Cancer Education

22-25 October 2014 • Clearwater Beach, Florida, USA

American Association for Cancer Education • Cancer Patient Education Network • European Association for Cancer Education

4-A: 2 – Living with and beyond breast cancer: issues of sexuality and intimacy

Joy Notter, Joy Hall


Birmingham City University, Birmingham, UK

Slide 1

Living with & beyond breast cancer:
issues of sexuality & intimacy

Joy Hall (Head of Department Public &
Community Health) & Professor Joy Notter
(Professor of Community Nursing)
Birmingham City University U.K.

International Cancer Education Conference
2014 – Clearwater Florida USA



Slide 2

Sexuality


"Sexuality is interwoven with every aspect of human existence, and in its broadest sense , sexuality is defined as a desire for contact , warmth, tenderness, or love. Humans express and live their sexuality in their daily lives. Sexuality is not limited to an act of seduction or if intercourse but encompasses every area of our lives: the way we relate to others, our friends, our family, and our work. It is evident in what we believe, how we behave and the way we look."

(Poorman, 1988)

Slide 3

Intimacy


- Cognitive or intellectual
- Emotional
- Sexual



Slide 4

Effects on sexuality


<p>Sexual function:</p> <ul style="list-style-type: none"> • ↓ Desire • ↓ Arousal • ↓ Dyspareunia • ↓ Vaginal dryness • ↓ Pleasure /orgasmic function 	<ul style="list-style-type: none"> • ↓ Sexual pleasure • Numbness of previously sensitive breasts • Reduced or lost pleasurable sexual sensations.
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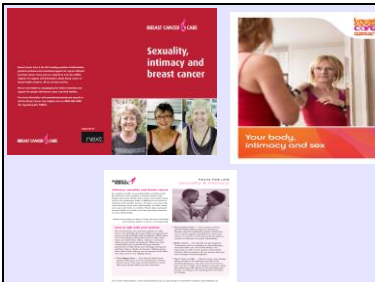
Slide 5

<ul style="list-style-type: none"> • ? Effects of tamoxifen • ? Role of reconstruction • Relationship context & sexual re negotiation 	<ul style="list-style-type: none"> • Sexual self concept & relationships • Need for holistic assessment
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Ganz, Desmond et al, 1998, Ganz, Rowland et al, 1999, Mortimer, Boucher et al, 1999, Knobil , 2001, Thors, Breckel & Jacobsen, 2001, Rogers & Kristiansen, 2002, Avis, Crawford & Manuel, 2004, Burwell, Speer & Hillenber, 2005, Case et al, 2006, Fobair, Stewart et al, 2006, de Costa Vargens ,2007, Takahaski, Onome et al, 2008, Markopoulos, Tsaroucha et al, 2009, Emileet, Ussher & Perz, 2010, Melsko, M, Goldman & Rugo, 2010



Slide 6



Slide 7



Slide 8

Review of lesbian & bisexual studies/literature

- Literature review adopting a Participant Intervention Outcome (PIO) approach was undertaken searching the Cochrane & Campbell Collaboration together with Medline, CINAHL, ASSIA, PsycINFO/Arts, criminology, & NELS (National electronic library of medicine) /NICE databases using specific search terms (sexually, sexual dysfunction – physiological & psychological, lesbians, homosexual women, bisexuality & bisexual women, sexual minority women, cancers – breast).
- Following the location and initial review of results from the database search only 15 articles matching the PIO criteria were located.
- Of these only 4 met the search criteria for critical review based on title and abstract.
- In addition, 2 studies identified lesbians as a comparative group to heterosexual women
- All subjected to critical review utilising the CASP critical appraisal tools.

Slide 9

Effects on sexuality, sexual health & intimate relationships

Lesbian Specific:	Lesbian comparative group
Boehmer, Potter & Bowen (2009).	Fobair & O'Hanlan et al (2001)
Boehmer (unpublished)	Arena & Carver et al (2007)
Boehmer, Clarke et al (2011)	
Boehmer, Timms et al (2012)	Lesbian's in participant group:
	Gilbert, Ussher & Hawkins (2009)

Slide 10

Health Care Professionals : The hidden relationship

"My partner had breast cancer and although the care she received generally was good, our relationship was never acknowledged and at best I was treated as her "friend", which at times we found difficult and stressful. We didn't like to say anything critical to staff about this because the important thing was that they behaved well to my partner and her care was good."


[Hunt & Fish, 2008]



Slide 11

Health Care Professionals : The hidden relationship

- Attitudes and perceived attitudes of health care professionals (Boehmer & Case, 2004, Hunt & Dick, 2008, DH, 2010)
- Importance of psychological caring and support - including disclosure of sexual orientation Boehmer & Linde, 2005, Fish, 2010, White & Boehmer, 2012)



Slide 12

Cancer educator's study

Aim:

To identify and explore the following:

- Attitudes of nurses and health care professionals towards lesbian and bisexual patients.
- Appropriateness of cancer services for lesbian and bisexual women.
- Assessment and interventions with lesbian and bisexual women and their partners in regards to their sexuality and sexual health.

[Hall, unpublished]

Slide 13

Results		
Number distributed		Response rate
40		20 % (n= 8)
Country of Practice		% & number
USA		25 (n=2)
Canada		12.5 (n=1)
Poland		12.5 (n=1)
Netherlands		25 (n=2)
Australia		25 (n=2)
Healthcare background		% & number
Doctor		25 (n=2)
Medical education		12.5 (n=1)
Nurse		12.5 (n=1)
Specialist nurse		12.5 (n=1)
Nurse/healthcare educator		12.5 (n=1)
Other		25 (n=2)

Slide 14

Sexuality & sexual health - generally		
	Yes % & number	No % & number
Ask about sexuality	37.5 (n=3)	62.5 (n=5)
Ask about sexual health	37.5 (n=3)	62.5 (n=5)
Ask about intimate relationships	25 (n=2)	75 (n=6)
Do clients/patients ever raise the subject of sexuality with you?	25 (n=2)	75 (n=6)
Do your clients/patients ever raise the subject of sexual health with you?	25 (n=2)	75 (n=6)
Do you deal with these yourself?	25 (n=2)	75 (n=6)
Ask them to see someone else?	37.5 (n=3)	50 (n=4) 12.5 (n=1 N/A)
If so who?	More senior nurse, doctor, social worker clinical psychologist	

Slide 15

Sexuality & sexual health - generally	
How comfortable to do you feel about asking questions about sexuality & sexual health with your clients/patients ?	% & number
Very comfortable	0
Comfortable	25 (n =2)
Uncomfortable	50 (n =4)
Very uncomfortable	0
Other	25 (n= 2) (out of date clinically, not relevant to work)

Slide 16

Sexual Orientation		
	Yes Number	No Number
Within your practice do you ask about the sexual orientation of your clients/patients?	25 (n=2)	75 (n=6)

Slide 17

Sexual Orientation	
If you ask how comfortable to do you feel about doing so?	% & number
Very comfortable	0
Comfortable	37.5 (n=3)
Uncomfortable	12.5 (n=1)
Very uncomfortable	25 (n =2)
Other	25 (n=2) (don't ask, more confident or changing perceptions of society)

Slide 18

Is there anything which would stop you from asking your clients/patients about their sexual orientation ?
'Not relevant to differential diagnosis'
'not relevant for my part of the trajectory'
' so far no need to ask about this matter'
' probably not – although I would be mindful of how I approached the subject'

Slide 19

Implications & future research

-

Slide 20

Hold my hand
John Taylor
Hospice. U.K :
Author unknown:

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References

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