Mantelzorg en dementie:

Paradigm shifts in Support for Dementia Care:

‘The Journey of my life’: destination unknown

Submitted in part fulfilment for the degree of Doctor of Philosophy

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Acknowledgements

This study turned out to be the crown on my more than fourty years of work. I have been able to use all my knowledge, experience and contacts to write this thesis. A crown in the double meaning is the interest of the royal house for the attention of young carers, the visits and the meetings with the King, the Queen and the former Queen of the Netherlands were a really great experience and formed a crown on my work.

First of all I am most thankfull for the enormous cooperation of so many carers who are caring for a loved one for a long time or did so in the past. It was heart-warming to experience their involvement and made it possible for me to really feel what concerns the carers have and what their experiences are or were.

Without the support and knowledge of Professor Joy Notter, Professor of Community Health Care Studies of the Birmingham City University this study would have never come to an end. Her experience and encouragement kept me going on and on again, following the chosen road that in my experience, never seemed to end. During this study I came in contact with Dr Stephen Wanless from BCU. He also supported and encouraged me tremendously and I thank him for that support.

Last but not least I want to thank all the colleagues and the supervisory board of Stichting Informele Zorg Twente. They have made it possible to start and complete this study.

To all the people in my professional and social environment who impatiently kept asking me when this study was finally completed, I would like to say this. The work I now have finished is not a completed study in itself but a completed and important contribution to an ongoing process in our society in which informal care will play a new but very prominent role within our healthcare system. Partly based on this study, a development has been set in motion that can no longer be stopped and is the start of a change that will affect society as a whole. We are only at the beginning. Everybody can at the moment see the enormous increase of attention for people with dementia and their carers in the Netherlands.
There is still a lot of work to be done. Let’s start with it!

Abstract

Introduction and background: This study is set in the Netherlands, and focused on dementia care in the community. Without exception, caring for a loved one with dementia in their own home is difficult and has a major impact on the carers own lives. Health and social care resources tend to focus on the patient with limited support for the informal carer, without whom the patient would be in full-time professional care. In addition the number of people with dementia in the western world is rising and will increase significantly in the coming years, with an accompanying rise in family and/or informal carers. There was limited information on the needs and wants of this crucial, and largely unrecognised group, a situation that needs to change if they are to continue to care for their loved ones in their own home. These factors were the rationale and motivation behind this study.

Aims: To gain insight into the motives, the needs and wishes of family/informal carers, caring for a loved one with dementia. To use this data to develop a conceptual framework and model that has the family unit as central and to make recommendations for policy and practice for Dementia care in the Netherlands.

Methods: This was a qualitative study**,** which used grounded theory to explore the lived experience of informal carers in the east of the Netherlands. Ethics approval was gained for the study. Participants were randomly selected from the data base of a care organisation supporting dementia patients in the community. A total of 25 individual interviews were carried out followed by focus groups of between 6-9 participants. In total 72 informal carers participated in the study. As recommended in grounded theory, data collection and analysis took place concurrently, with data collection ceasing once saturation was reached.

Findings: It was evident from the start of the study that the carers wanted to care for their loved one, but were struggling. They described caring as a 'heavy burden' and reported feeling ignored and personally let down by professionals. They wanted to be respected partners in care and be given the lead in setting up care plans, arguing that the care offered was not tailor-made for the patient, but designed to suited the professional organisations with the patient expected to 'fit in'. They desperately needed time for themselves, and emotional support, but felt selfish and guilty for thinking about themselves, with most reported that as the caring burden increased, so they had 'lost their own lives' a situation that urgently needs addressing if they are to continue in their chosen role.

The study revealed that for this group a major paradigm shift in care planning was needed with the family unit and the informal carer's role within it, given primacy over professional services. Currently the converse is found, with professionals seeing it as their role to define and order care services. The paradigm shift means that professional care becomes regarded as supplementary to, and not more important than, the role of informal carers and the care they provide.

Conclusions: The wealth of data was used to develop a model to empower informal carers, to help them recognise their own needs as well as those of their loved one, to give them the confidence to enable them to access support for themselves, and to take the lead in planning care and service delivery. The project also developed a series of individual activities that have gained national recognition and acceptance, these include a young carers project, an information video and package that gives information across the whole journey for the family unit, a training package for professionals, and regular Alzheimers cafes to support both informal carer and their loved one. However, the greatest outcome of this study is that the model and paradigm shift have been accepted for implementation on a national basis. This will begin in 2021, having been delayed a year by the COVID-19 pandemic.

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Glossary

Mantelzorger	The word has not been around for very long; it was conceived in 1972 by someone who was both a doctor and a divorcee, Professor Dr. Johannes Hattinga-Verschure (1914-2006). Defenition of a mantelzorger (carer) : informal care is unpaid and often long-term care that someone provides to loved ones, for example to a partner, parent or child. But caring for a neighbor, friend or acquaintance also falls under informal care. The informal caregiver has a personal relationship with the person he or she cares for.
Zorgvragers	Care recipients
Sociaal cultureel planbureau	social cultural planning office
objective of the social cultural planning office	Het SCP draagt bij aan goed geïnformeerd overheidsbeleid en een betere samenleving met wetenschappelijke kennis over het leven van burgers in Nederland.
Wet maatschappelijke ontwikkeling (Wmo)	Social Support Act
Doel van de Wmo	Objective of the Social Support Act: Municipalities must ensure that people can live at home for as long as possible. The municipality provides support at home through the Social Support Act (Wmo). Officially, this act is called Wmo 2015.
Wet langdurige zorg (Wlz)	Long-term care act
Doelstelling van de Wlz	Objective of the Long term care act:

	The Long-Term Care Act (Wlz) regulates heavy, intensive care for vulnerable elderly people, people with a disability and people with a mental illness.
Zorgverzekeringswet (Zvw)	Healthcare law
Doelstelling van de Zvw	Objective of the healthcare law : The Healthcare Insurance Act (Zvw) is a law that regulates compulsory basic insurance for insured persons. The health insurers are responsible for implementing the Zvw.
Veurmekaar betekenis 1	Meaning 1: For eachother
Veurmekaar betekenis 2	Meaning 2: Well organised
Informele zorg	Informal care: both carers and care-volunteers
Nederlands huisartsen genootschap (NHG)	Dutch GP Society
Alzheimer Nederland	Alzheimer Nederland Foundation
Doelstelling Alzheimer Nederland	Objective Alzheimer Nederland : Dementia affects more and more people. Currently, 280,000 men and women in the Netherlands have Alzheimer's disease or another form of dementia. By 2040 this number will have risen to half a million. Everyone has to deal with the disease: as a patient, as an informal caregiver or within the family or circle of friends. Alzheimer Nederland wants to work for them together with as many others as possible.
Centraal bureau rijvaardigheden (CBR)	Central office driving skills
Zorgstandaard dementie	Standard of care for dementia
Deltaplan dementie	The Deltaplan Dementia is the national program to tackle the consequences of dementia together. Prevent and cure dementia. Better care for people with dementia.

	Dementia-friendly society.
Stichting Informele zorg Twente	Foundation informal care twente
	Objective Stichting Informele Zorg (SIZ)Twente : Offer appropriate informal care support to Twente informal carers of all ages. Since 1989 we have been striving for a society where all informal carers are seen and heard and can care for and grow up in the healthiest possible way. Where this once started with a voluntary babysitting service, we have now grown into a knowledge center for informal care. The range offered by SIZ Twente has been (further) developed jointly with informal carers and supported by the latest research, methodologies and knowledge. The offer is divided into the four pillars; "Relaxation & meeting", "information & advice", "respite" and "knowledge sharing". Because we believe that we can only create an informal care-friendly society together and from different angles, SIZ Twente also offers appropriate programs and training to professionals and organizations.
Onbenutte zorgkracht	Untapped (unused) care power
Staatssecretaris	Secretary of State: A state secretary supports a minister in leading a ministry politically. State secretaries are mainly found in 'heavy' ministries. There they will be given a specific policy area under their wing, but the minister will remain jointly responsible.
Ridder in de Orde van Oranje Nassau	Knight of the order of orange nassau

Chapter 1: Introduction to the study

1.1 : Introduction

This study based in The Netherlands, was originally designed to develop strategies to improve the delivery of support services for families living with, or caring for a loved one with dementia and to make recommendations for national and local policies for systems to increase access to, and extend, support strategies for these families. The word dementia has been used throughout this study as an umbrella term for disorders characterised by progressive impairment of cognitive function. Today, in the Netherlands, of the population aged between 60 and 65 years of age, one in 200 (0.5 %) has some degree of dementia, but for those over 90 years the incidence rises to two out of every five, or (40%) of residents. National statistics demonstrate that currently there are some 230,000 people diagnosed as living with dementia. Approximately 35,000 need specialist nursing home care, with a further 20,000 living in residential homes and the majority, almost 175,000 still residing in their own or a family member's home. However, it is a major cause for concern that government estimates suggest that over the next 30 years the number of people with dementia will double. This, will increase the burden on families and on - what is already seen as an increasingly extended health care service. (Toegepast Natuurwetenschappelijk onderzoek 2012). Across the Netherlands, Alzheimer's disease is the most common cause of the development of a range of signs and symptoms affecting the psychological, emotional and ultimately physiological activities of daily living. The provision of appropriate support services has been increased because there is a strong relationship between age and dementia, and as individuals age there is an increased incidence in the development illness and disease, thus many individuals also have co-morbid illness that can be exacerbated by or can impact on the signs and symptoms that they display (Ministry of Volksgezondheid Welzijn en Sport 2012) Thus, in common with other Western European countries as the Dutch population ages, the incidence and prevalence of dementia rises. In addition, for those with learning difficulties, dementia can begin much earlier in life, with increasingly numbers of patients being diagnosed in their early 40's.

Although clinical dementia care in the Netherlands is regarded as being of a good standard, nevertheless, there are some problems. Carers of those still living at home report being faced with gaps in care services, limited information, and often not knowing whom to ask for what kind of support. (Ministry VWS 2009). Thus, many report that they are left struggling to keep their loved one at home for as long as possible without adequate help and support. As the disease trajectory progresses, to continue to cope they need to be able to make increasing use of professional (home care) organizations, but they find that no matter how much help they ask for, as the patient's condition deteriorates, the burden of care rises exponentially. To adequately address their concerns there has to be government recognition of the steadily rising nature and prevalence of their needs, which can then be used to shape the development of policy and practice. The challenge for health care provision is that currently, since the enactment of the Dutch Law on Social Support (Wet Maatschappelijke Ondersteuning , WMO 2007) the municipalities in the Netherlands have had to develop their own policies relating to family care, which includes the support of family carers. In consequence, since the full implementation of the WMO (2007) in 2015, the range and extent of services has varied across the country, with services for the patients and their families being offered through what appears to be a postcode lottery of care provision. This needs to be urgently addressed, the support provided should not be dependent on address but on national policies guiding, and where necessary, leading local policy. Then too, the national statistics increasingly indicate that it is not the progression of dementia in itself that leads to the breakdown of home care, but the exhaustion of the carer, either physically or psychologically (Ministry of Health Care, Wellbeing and Sports 2007, 2017). There is also evidence that once a patient with dementia has been admitted to fulltime dementia care they are unlikely to be permanently discharged, and that the less information and support the carer has had, the earlier the move into institutional care (Boer de et al 2010, Boer de 2005). National policies need to change to recognise that fear and uncertainty about the disease trajectory, and how it will manifest in their loved one disease or, whether they will be able to cope adequately, make the carer’s role much harder, increasing their need for support.

To improve implementation of national policies to underpin support services, there are a wealth of issues to be considered and questions to be addressed. Firstly, and of key importance for appropriate high quality care to be offered to the carer, is the need to develop in lay terms descriptions of the signs and symptoms that lead to a diagnosis of dementia, and what exactly the diagnosis means for all concerned. Families need to know whether the diagnosis given is early or late in the disease trajectory, who makes the decision and what it means in terms of daily living, communication, care needed and available support. On a practical level they need to know how to cope as verbal and non-verbal communication reduces, and to be supported as they try to develop strategies to overcome or compensate for the increasing absence of comprehension and response from their loved one. Also, for those living in the Netherlands for whom Dutch is not their mother tongue, there needs to be recognition and acceptance that in all probability as the disease progresses they will gradually lose their second language. This places an additional burden on the family who may have to gradually take on the role of interpreter with all care providers, other family members and ultimately with all those with whom the individual interacts. This loss of understanding of spoken language, particularly if health professionals use medical terminology or jargon can further isolate the individual, increasing their frustration and leading to withdrawal from previous contacts and activities at a relatively early stage in the disease process (Boer de et al 2010, Boer de 2005))

Having worked in the field of care and dementia care for over three decades, I have seen at first hand the changing but ever rising needs of individuals and families as dementia progresses. However, since the introduction of the WMO (2007) health policies, the focus of care has altered, with increased emphasis on the community caring for itself, with less reliance on central statutory services, something the families find hard to understand or accept. Employed as CEO in a local government organisation which supports family carers, the aim has always been to work with all families who provide informal care whatever the diagnosis of the patient. However, today one third of our workload consists of informal carers coping with a loved one with dementia, and their numbers are increasing rapidly. Across the Netherlands, organisations such as the one which I manage, are increasing, but still there are insufficient resources to adequately support the families. This is in part because the organisations are new, but also because the traditionally the health care professionals have focused on the patient's needs, with for the most part, support for the family/ carer being almost an 'after-thought'. Little time has been given to check on how they are coping and whether they have strategies in place that can support them until they reach breaking point (Sociaal Culureel Planbureau, SCP, 2010)

This study was instigated following my organisation's desk research that revealed that few appropriate strategies for developing community support existed and just how limited the current support services were. In recognition of the impact of devolving services to local government, and to give communities time to prepare, the WMO (2007), although drawn up and passed by the Government a decade ago, only came into action in January 2015. However, when this study began, it was evident that few local authorities had pro-actively discussed, let alone developed the policies needed to prepare for the planned major health reforms. There was little sign of change of use of funding or resources being moved away from the accepted institutional care, to increase home care, self-care and where possible self-sufficiency. The stated goal of including family members as well as the patient in new and existing care plans, was still just a stated aim, as the government had released no additional money for staff development or training for developing new supportive measures. There had also been little indication that any would be released in the foreseeable future. In part due to this lack of additional finance, no formal systems have been developed to identify the support needs of family carers, or the optimum points for increasing support services. The lack of pro-active initiatives meant the public have had no guidance regarding the WMO (2007) changes and family members often contact the organisation not even knowing what type dementia their loved one has, let alone what may have caused it, or what would exacerbate it. For families to keep their loved one at home for as long as possible, this situation has to change.

National and local policies and services have to be developed based on inclusive family centred care where the patient and the carer are integral elements of shared care provision, with the immediate and longer term needs of both patients and carers recognised and addressed. Only when this happens will carers be able to cope for the long term with the individual patient remaining in their familiar home environment. It is not sufficient to state that policies must change, action must follow the rhetoric, and systems be develop to implement the processes that accompany changes in service provision. There needs to be official recognition of the patient and carer as a single family unit for whom a single treatment/care plan has to be provided. Such a change in perspective is new, and unique in the Netherlands, where currently in health terms, the concept is only being applied to families with dependent children. To move to this approach, health professionals need to initiate support activities at the time the patient is given a dementia diagnosis, devising a tailor made support plan, which includes diagnoses needs of key family members, and whereby two inter-twined pathways integrate care for the patient, carer and where appropriate the whole family including young children. Only by utilising a shared diagnosis can the family dynamics be supported and maintained throughout the disease trajectory.

In many professional care organisations, as part of the WMO (2007) changes in practice, the role of senior care professionals or case managers has changed. Although as the job title indicates these managers were expected to co-ordinate care, due to large caseloads, they have continued to view the patient as central, have had little time to focus on each individual patient and even less to consider the informal carers. This has not only limited the care/support they offered, but left the carer on the periphery of service provision. Although they now have a stated responsibility for supporting carers as part of patient care provision, while the government recommendations are clear, as with much national policy, there is little or no practical advice or guidance on how to accomplish this. Nor is there anything on how to support the health care professionals themselves as their role changes and extends. They have to develop their own strategies to increase their access to and input with carers, without diminishing their role with patients, a lack of direction that must be addressed if carers are to receive much needed support.

It was in the light of this, that this study was developed, to respond to the identified gaps in provision being reported by informal carers. The changes needed affect all areas of care provision, from policy through to hands on care and support. It was evident that there needed to be a formalised structure that could be modified and used by different organisations across the country. After searching the literature and careful consideration, I decided that the development of a conceptual framework and model for practice which included practice guidelines, would offer education, support and advice (Ministry of VWS 2009). Therefore, the aims are:

- To collect, collate and utilise rich in-depth data sets to gain insight into the motives for caring, and the needs and wishes of (family) carers who are caring for a loved one with dementia
- To develop a conceptual framework and model that would accept that the family unit and not just the individual needed to be the focus for care.
- To make recommendations for policy and practice for Dementia care in the Netherlands

A format had to be found that was accessible and easy to use to help healthcare professionals work towards achieving their new targets and support all members of the families they serve based on the WMO 2015. Within it there had to be strategies to enable families to know how to access support and care for their loved one, to reduce the weight of the burden of care and through this help them to continue in their role for as long as they could. Thus, at the start it seemed to be a practical and needed study, which would enhance care provision in individual organisations (such as the one in which I worked), locally and ultimately raising awareness nationally. However, with hindsight this seems to have been somewhat naïve, because as the study progressed, it took on a life of its own, sweeping me along an exciting, but very humbling journey. Each phase of the study not only moved the project forward, but led to additional activities that exponentially increased individual, family, local and national interest and participation.

Over the lifetime of the study, areas not even considered at the start had to be included, and new and innovative systems were devised and implemented. Young carers, a group that until recently were unrecognised as providing care for dementia patients, were brought into the project, with local and national initiatives to support them and address their very specific needs. Dementia support cafes were set up to support carers and patients, and training programmes for professionals were developed and carried out. From within all age groups there were participants that transitioned from willing contributors to active mentors and guides for their peers. As participants shared their experiences with friends and their extended family, the news about their activities spread, with local and national politicians starting to ask questions, wanting to learn more, and also asking for advice on how to change practice. As a result of this, the national media became involved, developing a documentary for young people, and setting up question time type panels. A dissemination conference was held at which both the First and Second Chamber (equivalent to the House of Commons and House of Lords) were represented, and organisational leaders from across the region publically gave commitment to the implementation of project strategies and activities.

A project team was set up to help with implementation as no one person could carry out all the activities, they were consistently hard and won national awards for their activities, the King of the Netherlands, as protector of a fund for needs in society, heard about the activities and asked to visit to young carers initiative. He and his advisors met with participants following which, after careful consideration, the project was awarded the prestigious national 'House of Orange' award. Unexpectedly, I found I had become recognised as a local and national expert in the field of dementia and was and still am frequently contacted for advice and guidance. As exciting as all of this was, for me the culmination came when in recognition of the positive impact on dementia care in the Netherlands this project had had, two unexpected but nevertheless very welcome accolades were handed to me. Firstly, I was made a Knight of the Order of the House of Orange, secondly, in November (2018) the government formally issued a briefing document that contained all the essential elements of care and support developed in this project. This has now moved further, and become accepted as government policy with the measures set out in the 2018 dictate being the first steps for implementation towards the end of 2019, and full implementation planned to start in the summer of 2020. This very welcome, but totally unexpected government acceptance of the findings of the study, provides the opportunity for a major overhaul of all support services, thus closing a circle of differing areas of provision and joining what, as the study progressed, had appeared to be many different routes or roads for the different groups of informal carers and professionals to follow. Thus, the outcomes of this study are now firmly embedded in national plans and supporting policy development and strategies for dementia care, a situation beyond my dreams when I started the study. All the activities arising from the project will continue, and even as this is submitted, the project is moving further forwards with future research and new initiatives already identified.

Every effort was made to maintain transparency throughout the study, with all those who participated informed of every step, and presentations made to groups of project findings and new activities. The participants stated that they needed to 'see' how all these new activities or 'new roads' linked together, and following discussions with them, as the project had developed into journey, the diagram given below was developed. The families I work with and the participants described me as the link that joined everything together, and after repeated requests, as this was a participatory study, I finally agreed to put myself in the position they suggested.

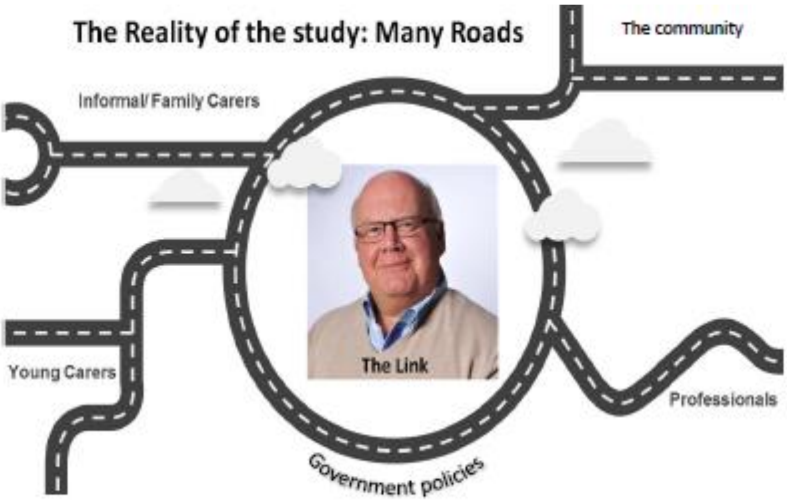


Figure 1.1 Many roads

1.2: Planning the study: Positionality

The starting point for any study in a sensitive area such as dementia care has to be recognition of the background, the knowledge and life experience of the researcher, and how these will affect the design, planning, activities undertaken, and outcomes of the research. Increasingly referred to as positionality, the formalised recognition of the impact of the researchers on the research process and research outcomes supports transparency and auditability as well as helping to address and minimise bias (Hopkins 2007) In positivist research an assumption is made that the researcher's stance is objective and outside the research process, but it is increasingly being recognised that within all research there is an element of bias that needs to be identified and addressed (Bryman 2008). In contrast to the positivist approach, the inductive processes used in interpretivist research have always accepted that by definition, the researcher is actively involved in all phases of data collection and analysis. As Denzin and Lincoln (2011) point out, the aim of qualitative research is to explore specific phenomena in depth, and part of this includes reflecting on how the interactions between researcher and participant(s) develop and impact on the study as a whole. Nevertheless, until relatively recently there was no formal process to acknowledge or describe the direct or indirect influence of the researcher (Vanderback 2005). By gathering together the different debates on subjectivity and objectivity researchers can use them to identify the positives and negatives that arise from their interactions during the research process (Hopkins 2007, Bryman 2012). As a consequence, qualitative researchers, especially those working with marginalised groups, are increasingly called upon to acknowledge and reflect critically upon their position within the

research in which they are involved (Hopkins 2007). Thus, a critical reflexive stance, with attention for my own positionality was a crucial element throughout this study.
I started my work forty years ago as a qualified nurse, based in home care. In that period there were already an increasing number of people with dementia living alone or living with their loved ones. However, it was also evident that there were by far, not enough places in nursing homes which specialised in care for people with dementia, nor were there sufficient expert health professionals for individuals and families to consult. Therefore, to me it was evident that the burden for carers as they tried (in many instances without support), to continue to provide care at home while watching the dementia progress, caused more and more problems. The outcome of these problems often resulting a position whereby they were unable to continue to care and had with reluctance, to accept their loved one needed institutional care. These difficult situations first encountered so many years ago, have to my dismay continued. The result is that, even as services have expanded they cannot meet the ever increasing needs arising from the increased numbers of people with dementia and the challenges faced by their loved ones and families. It had to be a major cause for concern that with a service that cannot meet current community and home care needs, the changes in social policy and care provision arising from the implementation of the WMO (2007) mean that more and more people with dementia are expected to remain living in their own, or family member's home and cared for by their loved ones.

I have never lost sight of the key role of the nurse, and have always tried to improve the services offered to people with dementia and still living at home, developing specialised teams of nursing with a remit of offering continuous support from specialist professionals. These teams are crucial for families/carers to be able to continue in their self-appointed but, on the whole willingly adopted roles. Carers report that at times the burden seemed to be so heavy that much as they loved the individual they looked after, they wanted to flee their home, and be freed up from the care and anxiety that they permanently lived with. The conflict and guilt that they express over feelings that they thought they shouldn't have, together with the sheer exhaustion of caring twenty four hours a day, seven days a week compounded the situation. Working with them the aim was to find strategies that would help the individual, but it was evident that these were in fact a drop in the ocean of need and that there needed to be a better and more sustainable way to work with, and support these vulnerable families.

When considering the study, it was clear to me that I was in a unique position because as a **community nurse** and **manager** I brought with me two complementary skill sets that could be harnessed to bring about change. However, for changes in care planning and delivery to be accepted, implemented and sustained they needed to be evidence based. I needed to make sure that my experiences and concerns as a nurse, for individuals and families, and my role as a manager were not adversely biasing my approach. Changes could not be based on my perspectives, but on those of the individuals and families I was seeking to help. It was essential that it was their agenda that was addressed, and not mine so that activities that I undertook did not increase the burden on carers and exacerbate an already overburdened group. To help avoid the risk of this I decided that an academically supervised study was essential, and thus began my role as a **researcher.**

Once the study was agreed and planning began, it was immediately apparent that having three roles led to some interesting and somewhat conflicting internal debates. Each of the three roles has its own strengths and constraints. As a **community nurse**, over time my knowledge and expertise had moved from being seeing dementia as a mental illness, to a much more positive perspective where I focused on mental health. I no longer saw the individual with dementia as a patient with a family, I now saw them as a unit within which each person had their own strengths and issues which impacted on their and their family's mental health. However, this focus could best be described as being at the micro level, with the focus on working cost effectively with the individual family unit.

The manager had a very different perspective, in this role, the aim was to make best use of the available facilities for the total workload of the care organisation. Cost benefit analysis and evaluation of measurable outcomes was key. Strategies had to be developed that fitted within the local implementation polices of the WMO (2007). There was acceptance that this 'new' plan for community care came without additional funding for education and training, and with limited funding for innovation and change. The result of this was that implementation of any new services in one area would mean reduction in another, all at a time where there was knowledge and acceptance of the reality of shrinking finances. Within a context of growing need, insurance companies have tried to contain their expenditure to fit within their cash flow a position which is hardly likely to change in today's current financial climate. The current care provision was designed to minimise negative changes and limitations of services across the total caseload, so functionality for the manager the focus had to be on a meso level, while keeping a watchful eye on the national or macro level.

The researcher had yet another view, that for services to be changed to meet the needs of the client group, research was needed that could be fully evaluated and considered for wider dissemination. Only that way could it be used on all levels, with focus on the need for all outcomes to be framed in a format that facilitated macro level service development. However, the researcher was also aware that this study was only possible because of the specialist skills of the community nurse. The nurse as a researcher- interviewer was aware that there had to be a balance between listening and reacting, with respect shown at all times to the interviewee, and gaining rich in depth information from facilitating and supporting discussions. This meant a balancing act between individual feelings, gathering the needed data, allowing professional feelings to be evident during the interview, continuing the conversation and not distressing the interviewees. Then too, there was a need to create a safe environment for all involved. Thus the focus here was all on the project, its aims and activities, and the researcher skills needed, not on the individuals, family units or management issues.

For clarity, each of the three perspectives have been given different colours, which have been used throughout the study. Having identified these differing but equally important roles, it was decided that a reflective journal needed to be kept to record, not only how the study progressed, but how the three roles complemented and contrasted throughout the study. Also that for clarity and provide the rationale for any specific changes in the study, extracts from the journal would be included where appropriate to illustrate the different perspectives and how these impacted on the study. In summary it was evident that:

Levels of action

The nurse wanted to act and solve or reduce the difficulties and negative results for carers who were trying to care for a loved one on a micro level

The manager wanted to solve or reduce the negative results of caring not just for one person but for all the carers in the workload and therefore chose to act on a meso level and monitor the macro level

The researcher wanted nothing less than to carry out the research and work with the results afterwards on both a meso, and macro level

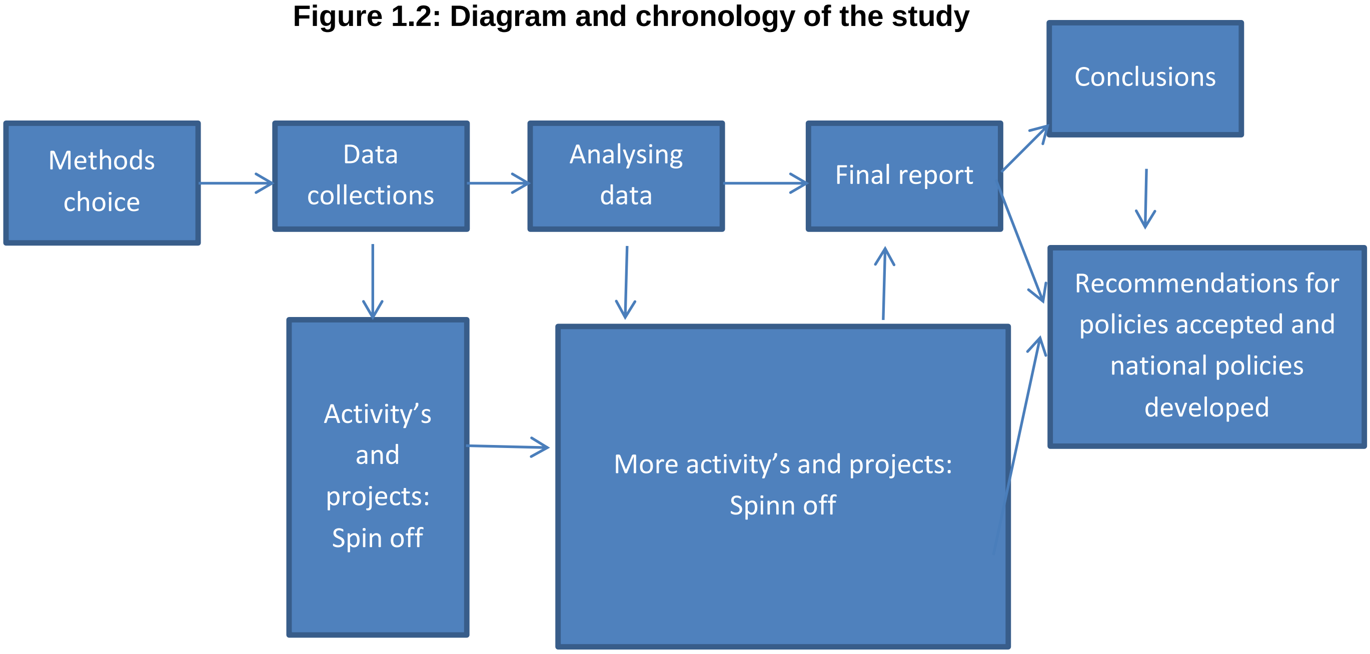
A totally unexpected outcome from this study was that as it progressed, interest in the outcomes increased, and I became increasingly known locally and nationally. Consequently, by the end of the project I had become recognised as a national expert in the field, and achieved what could be described as ‘celebrity status’ in health care. However, by that time all the data had been collected with feedback and dissemination well in progress (which was where the recognition came from). Therefore, reflecting on my positionality, while national recognition has helped acceptance and implementation of the study, it did not affect participation.

1.3: Study design: Identifying an inquiry paradigm and choice of method

Planning the study, it was seen as essential to recognise that any care for an individual with dementia does not stop while the loved one is alive. Care changes but continues when s/he is transferred into a nursing home, where statutory processes of caring are implemented and take over the carer role. Thus, these changes do not negate the need to focus support on all key members of the defined family unit, who in addition to the issues surrounding their loved one, are now bereft of the lead carer role that had become over time, their main raison d'etre. The focus of this study was on the total family/ caring unit regardless of the place where the individual patient resides, be it in their own home, day care, or a residential/nursing home. Thus, throughout this study, the term family unit refers to those individuals closest to the person with dementia, and may be immediate family, relatives or friends.

To collect, collate and utilise the data needed to move forward in partnership with patients and their families, the positivist approach with its deductive reasoning (Bryman 2012) was not seen as appropriate, Instead it was decided that interpretivist research with its recognition of the role of the researcher as an integral element of the project and the rich in-depth data it offers (Jamshed 2014) would facilitate exploration of the specific issues with key informants. However, the nature of qualitative research is such that it is axiomatic that fixed objectives are constricting to interpretive enquiry (Berg 2004) .Therefore, in this study, for each specific component, specific aims or key questions were developed at the time in which the data was collected. As the study progressed each stage of data collection led to the next, so for clarity an overview of the way in which all activities were linked has been given below.

Figure 1.2: Diagram and chronology of the study



This linear diagrammatic representation illustrates how the study became a somewhat complex journey over time, during which the main and planned steps resulted in actions and activities that were not, and could not, have been anticipated. These have individually and collectively have been accepted and have contributed to the local, regional and national acceptance of the study outcomes, and the identification of the measures needed for sustainability.

This research into the support of caregivers of people with dementia was urgently needed. Their position has to be improved and the support possibilities must be expanded. Only when that happens will informal carers be able to continue to care for their loved one with dementia (which is what most caregivers say they wish to do). There is much to be found in the literature about the phenomenon of dementia, but little focusing on the impact of dementia on families /informal carers. In the Netherlands, research there has been some research among informal caregivers, and how they are supported, but it focuses on caring for those with physical illnesses /conditions, and there is very little specifically exploring the issues that affect informal caregivers of people with dementia. In the absence of information and research, a qualitative approach was seen as most suitable. As informal caring involves changing roles and social interactions, symbolic interaction seemed appropriate, with grounded theory, which evolved from within symbolic interaction used to collect analysis and apply the findings. Using this, data retrieved from one interview is included when planning the next as the researcher seeks for saturation and ultimately consensus. As the interviews progressed, newly found items were added to later interviews, with informal caregivers encouraged to explore their concerns and describe and discuss their experiences. It seemed from the responses of participants that this was the first time they had been asked about, or invited to share their own perceptions of being an informal caregiver, or the impact their situation had had on their families. Attention was fully focused on them and not as they were used to, on the person with dementia, those contacted were keen to participate, and numbers sought were found in a very short time period. They were then asked whether they would prefer an individual interview or would like to participate in a group interview in a focus group.

To contact potential participants, the registered data list from the Informal Care Twente Foundation, was used. Randomisation of this data base of informal caregivers of people with dementia was used. It included informal caregivers who were currently caring for their loved one with dementia or had done so in the recent past. They were invited to participate and asked to choose whether they would prefer an individual interview or would like to participate in a group interview/ focus group. The interest among the approached informal caregivers to work with was so enormous that there within a very short time there were sufficient volunteers.

Saturation became the guiding principle for the number of interviewees, and interviews/focus groups were continued until no new issues arose. Ultimately, 25 individual interviews were conducted and then 48 caregivers were interviewed within nine different focus groups that were organized locally. In total, the data were collected from 73 informal caregivers in the Twente region.

As the research gained momentum, unexpected responses from participants were on occasion so powerful that they impacted on the whole study, as information was shared that elicited major problems with the support and care the informal carers received. Each time, this led to a paradigm shift, and in consequence from almost the first moment at the data collection, the researcher was confronted with the different perceptions that arose from the three different roles.

First of all, the nurse wanted to act immediately, wanted to solve the problem, and wanted to provide good care.

Then the manager wanted to come up with solutions for the problems found, but not just for one individual or family, but for the whole group of people the organisation served.

Finally, there was the researcher who wanted the research to be completed, after which actions could be taken on the basis of the outcomes.

Eachtime dilemmas arose regarding actions that needed to be taken, the community nurse always won. While this meant that care and support improved, it led to repeated delays in the progress of the research study itself..

The descriptions revealed repeated that informal carers experienced interruptions cross roads, unforeseen exits and turns along the route. The informal carers clearly needed directions guidelines and information to help them follow the twists and turns that accompanied the journey they had started. However, as the study progressed, it seemed that the actions and activities that arose in response made the study itself into a journey. A journey that turned out almost to have a life of its own, as every effort was made to find actions and where possible solutions for these informal caregivers. By the time the research was complete the journey that had become not just the journey of their lives, but of mine also. No less than 20 different actions were instigated some with for individuals, but some with a huge impact. These included national acceptance that caring for a loved one is not just the job of older caregivers. Young people can and want to be involved in any care plan for their family, but it is essential that they understand the situation, and have their own support system.

A national policy change is in progress which will change support for informal carers across the country. It has been nationally accepted that everyone in the same household, everyone in the immediate caring vicinity is an integral part of the living unit and must be involved in any support plan for the whole living unit. Supporting informal carers does not only consist of offering support options but should be focused on the empowerment of informal caregivers. Helping them to understand the situation, not to be afraid of it, or to feel the need to run away from the problems, but to face the actual situation with help and support at all stages. If informal caregivers can face their situation, they can indicate for themselves what would help them to take care of a loved ones. They need to take control for themselves and determine what they can and want to do as a (central) caregiver, to indicate who comprise the living unit, and how all individuals link and support each other. Also, additionally, once they have started to give informal care, where and when do they find it necessary call for professional help. From informal care support to empowerment. This requires a completely different approach to professional care.

1.4: Outline of the thesis.

To demonstrate how the study developed and how all the activities were interlinked, the outline of the structure of the dissertation given below describes the separate chapters. It consists of nine chapters.

Chapter 2 This chapter sets the scene of the Dutch context of care, mentioning the legal structure and policies of the country, the organisation of health and social care and the situation regarding dementia, and dementia care.

Chapter 3 describes the content from the literature for both the carers and the dementia phenomenon. It became clear that there is a lot of literature available about dementia as a phenomenon, approached from the theory of disease. There is also a lot of literature on carers and informal care available. The exact scientific basis for carer and dementia has not been extensively documented.

Chapter 4 deals with the chosen method: grounded theory. Why the chosen method was used, the theory, the design and planning of the study are extensively discussed as well as the method for data collection. The sample group are described. This chapter then discusses the analysis of the data as well as the trustworthiness and ethical considerations.

In chapter 5 there is a step by step discussion regarding the outcomes of the interview are, the added questions and the way in which the study was interrupted because action had to be taken with the results found. This chapter discusses an impromptu event which focussed on a new way of supporting informal caregivers, in this instance that of young caregivers, which was developed, implemented and was paid recognition by the Dutch Royal family. The results are presented and analysed. Finally, the key themes are described and discussed.

Chapter 6: in this chapter the development of the model is described. It is based on the content found and discussed in chapter 5. With the theoretical input about empowerment and change management the model, the conceptual framework, arises and is shown.

Chapter 7 deals with the new ways to support carers. Many new trends that are described per topic. Here, the paradigm shifts that were found are discussed. New ways of support are also described.

In chapter 8 the national acceptance and implementation of the developed model into the dutch dementia care services is described.

In chapter 9 the personal reflections are described

In chapter 10, the critique of the research are reviewed. Both personal development and professional development of the researcher are described. The results from each subproject, the state of the art so far are also described in this chapter.

Chapter 9 then discusses the conclusions and recommendations. It is clear that this study does not stop there, but has a major impact on the changing situation in the Netherlands.

1.5: Summary

The number of people with dementia in Western Europe society is growing rapidly. This is due to in part due to the demographic changes with ageing populations with the number of people with dementia in the Netherlands predicted to increase to more than 500,000 over the next 25 years. In the vast majority of situations, an informal caregiver is involved in the care of individuals in this group, with these caregivers carrying what they describe as a heavy burden that continues 7 days a week, usually for 24 hours a day. This study was designed to support carers and it is therefore fitting that the title came from what the carers themselves said. They repeatedly The participants repeatedly referred to their lives as being a journey, one that they could not see the end of, and found very hard because they did not know where they were going, how long it would take, and could only see life getting harder and harder. The metaphorical comment below given by one participant is one of the clearest examples of what became the guiding principle for the research.

'Caring for my husband with dementia was really a journey … to an unknown destination…. you know where you started… but you don't know where you are going… and if you don't know that…. how can you take the right luggage with you on the road…. '

No two family situations are the same and thus, the journey is different for everyone, and in consequence the 'luggage' (support), needs to be different for everyone. For the informal carers it is difficult to follow a journey with an indefinite destination, where they do not know the many possible exits and new discoveries, and that is heavily reliant on their ability to be flexible and adaptable. Many are struggling so hard to cope that they have little time to indicate where and how they need support. The professionals need to travel along with the informal carer, they have to stand with the informal carers if they are to identify and meet their need for support. As this study progressed it too needed to adapt to meet the emerging issues and concerns, some changes involved full paradigm shifts, and where this happened, the reasons and actions the followed have been discussed in the findings. Looking back at this study, the main research was completed but the work has just started and actions and activities of the journey continue. The conclusions and recommendations are now embedded within national policy, and practice changes have begun. There is a world to be gained in facilitating, supporting the living unit as they care for a loved one, and so much work still to be done..

Chapter 2 The Netherlands Context

2.1: National structure

The Netherlands has an excellent standard of Dutch healthcare, according to the Euro Health Consumer Index (2017; 2018), the ‘industry standard’ of modern healthcare for the best healthcare services for the last two years it has topped the list of the 35 countries. It is ranked ahead of larger economies such as Switzerland (2), Germany (7) and the UK (14), and is the only country that has been consistently placed within the top three positions for over a decade. The index, states that the Netherlands excels in relatively every healthcare criterion they assess, and that the high position has been maintained, in part, due to the increased accessibility to all health services though the opening of 160 primary care centres. These new centres, now offer 24 hour access to services, 7 days per week.

The Netherlands spends around 11.2% of GDP on health, and for all Dutch residents, health insurance is mandatory, with provision covered by four statutory arrangements:

1. Zorgverzekeringswet (Zvw) – often called ‘basic insurance’, this covers immediate/ acute or emergency medical care. (Cure)
2. Wet langdurige zorg (Wlz) – this covers long-term nursing and care. (Care)
3. Wet maatschappelijke ondersteuning (WMO) – covers every health and social care day support services offered by the local government, such as household help, cleaning and cooking for those who need additional care. (Care)
4. Jeugdwet – covers short and long-term medical care for youths under 18 years old.

As this suggests, under this fourfold system, while Dutch residents and employees are automatically insured by the government for long-term nursing and care (Wlz point 2), it is the individual insurance policies that cover basic healthcare. As this system is the route into the National Health Service, if an individual does not have their own health insurance, they risk being fined by the government. Young people under 18 years of age can be covered by a Jeugdwet policy (point 4), or by their parents’ policy, but for the latter, parents need to inform their insurer that they want their children included, or the child will have no basic cover, and parents can be fined for not providing adequate cover. Although carefully designed, within this system, there is one major constraint, individuals who need to access care and support services (under WMO point 3), first have to be assessed by government appointed officers. These officials ascertain firstly which services their family or friends can provide, and where they think the gaps in provision are. Only once these have been assessed and recorded, can any care services be assigned for delivery by local providers.

The system, although complex is well regulated, and to protect individuals from fraud, health insurance can only be purchased from registered providers. The government description of “private health insurance with social conditions” does not really explain or clarify the system, as it not a private scheme, but a national system which, like the NHS UK, covers the total population. However, instead of money deducted at source as it is in the UK, individuals have to personally contract with a company, much as private health care insurance is purchased. All Insurers are tightly regulated for quality, provision of basic services, and prevention of discrimination. They are required to accept all residents in the areas for which they provide insurance, charging a flat rate, no matter the individual’s health status. It has to be recognised that these are businesses not charities, so, to prevent a loss of profitability from too many chronically-ill patients, a system of risk equalization has been developed. Insurance companies can use this to apply for financial compensation for providing services to patients with high health needs and costs.

Interestingly, while the insurance companies are legally bound to accept all residents, the converse does not apply, if a citizen wishes to change their insurance company or to buy additional health insurance (which gives them additional benefits) they are free to do so at any time. This is described by government as encouraging competition between companies, with the regulatory processes preventing them from accepting only healthy patients, and from finding strategies to minimise the cost of health care provision to individuals needing more complex, expensive and long term care services. The ministerial aim of the system is to support the delivery of cost effective, high quality, excellent care to the populous pre-existing conditions or health status. They argue that while they refer to it as ‘private’ insurance, this approach is in direct contrast to countries such as the USA, where incentives are used to encourage the healthy to join, and reduce acceptance of high cost patients. As a further measure to protect and facilitate patient choice and rights, the Dutch government runs a website individuals can make comparisons between the different insurance companies and hospitals, based upon ratings for quality, health outcomes and national performance indicators.

As almost all Dutch health care professionals speak excellent English, healthcare in the Netherlands is accessible for immigrant patients and families, and for visitors from other countries, whether on holiday or business. However, there is a constraint in that in most instances to access the Dutch healthcare services a form of health insurance is mandatory, For EU member states, reciprocal government agreements are in place for emergency treatment, but these are not meant for long term ongoing care and if the individual wishes to stay for treatment and care in the Netherlands, even temporarily they will need additional insurance cover.

2.2: The political context

The social support act or WMO (2007) was designed to increase support for, and maintain the integration of people with mental or physical health issues and/or limitations in their own society. It was passed as part of major health insurance reforms, introducing a new scheme covering care and support in cases of protracted illness, inability to return to work, or diseases linked to ageing. The act emphasises individual responsibility in health care, both in insurance terms and regarding the provision of social and health care. Within this concept, the government has been able to formalise the establishment of the standardised basic health insurance schemes for the entire population, list in the previous section. However, the new Law brought with it, sweeping changes in access to, and implementation of, care provision, so although designed and passed in 2007 (part 1) there was acceptance that preparations needed to be made nationally and locally for these changes, and therefore full implementation was planned for 2015 (part 2). This move to decentralise from national administration, gave municipalities/local governments' total responsibility for home care, for support and initiation of care, as well as regulating transport, and the various subsidies for which individuals and organisations can apply. The challenges inherent in such a major transformation of service provision were compounded because at the same time, the Exceptional Medical Expenses Act (AWBZ) was modernised, and implementation processes revised. The combination of these changes meant that for the first time, the local authorities had to take a leading role in the implementation of the Law governing health and social care

There was government expectation, that in the eight years between approval and implementation, each of these would have developed their own local policies, and be ready to take responsibility for the financing and contracting of all WMO based activities. This included to establishing offices to lead the organisation of care, cure and welfare, and for systems for the evaluation of the quality of care. Care providers were for the first time able to negotiate specific contracts with local government, the aims of which were design and implementation processes for proactive and community driven intervention programmes. It was argued that these would strengthen the relationship between providers and clients. However, in the event, it was evident that by 2015 few local authorities had progressed the processes they now needed and thus implementation has been patchy and in some instances gaps in provision have emerged that urgently need addressing, with elements of dementia care in this category.

2.3: Services for those with Dementia

The move to local government for the care of all older/ frail elderly patients remaining in their homes and for the support of their carers includes dementia care. However, there is now a contradiction in service provision that is confusing some of the families trying to access services. The institutional care provided by nursing homes remains out with the responsibility of the local government, but the support of carers with a loved one who has dementia and has been placed in a nursing home is now within the jurisdiction of the local government. Thus, although in policy terms the care for patients with dementia appears to cover all eventualities, under the new system the support of their carers is somewhat convoluted with different components organised by different statutory and voluntary organisations. The result is that frequently, no single integrated care plan for the overall family unit (this includes both family and patient) is evident. Instead, there are a myriad of separate plans which may and often do, duplicate or omit elements of the needed services both for the care of the patient with dementia and for the support of the carer(s) and family. The government has stated eight basic functions/needs for support of carers that have been agreed by the various national organisations and concerned parties, which include the Ministry of Health, Mezzo and the Association of Dutch Municipalities, but as the summary of their documentation given below indicates, this is not clear, or easy for service providers, never mind patients and their families to navigate

The first ‘basic ‘need that they list is **information.** This should focus directly on the individual caregiver, but overall it has to be accepted that it also has a more generalised and indirect function. The argument is that information needs to be disseminated to a wide audience if awareness of the importance of care and the need for supporting carers is to be successful. The remit includes:

- general and family enquiries about caregiving, diseases, conditions, limitations, disabilities;
- patient enquiries regarding offers of help, support, and care (facilities and providers);
- Information on local and national legislation.

Local authorities can access and utilise the (WMO- government or branch) offices (oral) information on caregiving, they can also refer people carers Care Centres or voluntary organizations etc. However, despite the recent publicity and government campaigns people often do not recognize the term "caregiver" itself, and reports suggest that even when they do they are struggling to navigate the wealth of materials available as they seek to find specific programmes and pathways that they can relate directly to their own situation. Thus, although approachable forms of information are reported as being available for all groups to use for ‘self-identification’, the policy maker’s opinion of accessible would appear to be at variance with the perspective of the clients’. Policy makers and information providers need to recognise that if the individual who has limited free time (because of the very nature of their loved one’s illness), does not clearly and easily see their way forward he/she will give up and try to struggle on alone. Then too, some individuals are not comfortable searching out or reading the digital information, which can be found in what is described as the ‘social map’ of the municipality, indeed many do not even recognise what that is, or that it may be an appropriate information source. This may be a generation issue with younger clients happier with digital media, but for now, there needs to be acceptance that current systems are not working and there should be a move to regular reports in local authority journals or in the local newspapers in a format that is readily and easily accessed and understood.

The second need is described as **advice and guidance**. It is evident to healthcare professionals in practice that many carers need more than just information. A listening ear is often of primary importance and helps them articulate the support needed. Only when they are clear and comfortable with their self-identified needs and wants is it then possible to offer guidance in a manner that enables them to navigate their way through the large number of possibilities, and helps them to make appropriate choices and approach the relevant to authorities. The key element is for healthcare professionals to have accurate and up to date knowledge such that they can give detailed advice and guidance in a format that can be accepted and then utilised by the individual, as they work in partnership with providers to develop individualised care plans. These need to be combined into a long term integrated plan for the caregiver / family. However, there is evidence that this is still just an idea, with little evidence of any such detailed family care cross the country. The basic structure as presented in policy plans is supposed to consist of consultation and anamnesis as a first step in the support process. The next step is the identification of the needs for support for the carer at that moment. This can be material, financial or practical and emotional support and assistance. The need for a professional case manager to provide help in this process is seen as a need. The case manager should involve the household with children as a unit and not only focus on the key carer.

It was disappointing to find so little progress in this essential area, as the local authority can choose to give advice in partnership with the WMO officials, so obviating the need for the individual to make separate applications and minimising duplication and omissions. The Local authority can also choose to work in consultation with local partners to check that appropriate advice is given to the caregiver and guide. Only when care support includes all possible players and provides centres that individuals can freely access should play a crucial role in carer/family support, and this limited basic function/need therefore urgently needs full development and implementation.

The third, **emotional support** is being increasing recognised as one of the most crucial support needs. It goes well beyond the access to a listening ear mentioned above. Care, disease and rapidly changing perspectives need specific individualised on-going emotional support because the emotions they experience when caring for and watching a loved one deteriorate make it difficult for carers to cope without becoming overloaded in the short term and overburdened in the long term. Health care professionals need to accept that for the carer, the function of emotional support cannot usually be separated from the practical functional wants and needs that they have. Thus, emotional support needs to be offered at all stages from diagnosis onwards. It can be offered individually and/or in groups. It can include, Walk-in centres, Individual guidance, Peer support groups for carers, Family care cafes/salons / bars, Pampering / leisure activities specifically for carers, Chatbox / SMS services, Friendly visiting teaching services and perhaps one of the most effective strategies, Buddy contacts, such as friends and buddy care service. Emotional support may be needed by- and should be offered by anyone who has contact with the caregiver. These may be people from their own environment / circle, care assistants, care support centres, but also counsellors from churches and voluntary organizations such as the Sunflower and the Dutch Red Cross. Openings should be sought for personal discussions which can in turn lead to the instigation of emotional support.

Next comes **education.** Caregivers can benefit from specially tailored education and training to help them develop strategies and mechanisms which goes beyond information and advice and currently is usually offered in groups. Many carers report finding additional emotional support from these the education setting, sometimes because participants are already friends, but also because they may become friends as the programme progresses. However, for some this approach is not suitable so it could and should be considered for provision on an individual basis. Such education can focus on care and disease, but should include a focus on the caregiver themselves. The basic programme consists of education in health and disease, setting self-limits / care of yourself / empowerment, increasing expertise on care and support. Instructions/ protocols for the correct use of clinical appliances and/or practical skills training, and Specific courses on diseases, disorders, coping with illness (e.g. dementia or psychoeducation). Overall its aim is to provide appropriate educational support for and to caregivers, staff from local authorities and local organizations. It can be delivered in for example, informal care support centres, the patients groups and can include expert input by professionals such as social workers.

In the Netherlands for families with a member with dementia, **Respite care** is the collective term for provision that provides temporary care, taking over all aspects of care so that the family caregiver can pause to take time for the care of his/her own needs to try to guard and maintain their own health. It includes a range of strategies designed to help them to develop different coping mechanisms the help reduce the stress and burden of their carer role, and can include exercise regimes, relaxation techniques or other measures that they identify as helping them unwind and reduce stress levels. The challenge is that currently there is no standard definition of which facilities can be accessed by whom. Different areas and local councils have different thresholds for respire care, and this inequitable service urgently needs to be reviewed and to develop national standards that apply to all client groups wherever they reside, and that clearly stated what is feasible. To truly implement respite for caregivers' policy makers need to recognise and accept that one size does not fit all, and that support strategies need tailoring to the individual family unit. Also that emphasis needs to be placed on removing the guilt that many carer report feeling whenever they take time for themselves or join in activities that they see as outside their role and function.

However, currently the challenge is the nature of the existing application forms, they are complex, confusing and not quick to complete, this when for the individual, time is at a premium and they are already exhausted, which in turn further affects that ability to access and complete the forms correctly. Their struggles and frustration need to be recognised and resolved as the importance of respite care cannot be over emphasised. Policies alone are not enough, there needs to be clear and detailed information on request, this needs to include indicators, funding, timescales, examples of how to complete templates and support staff for carers to access at need. Guidance needs to include a strong invitation to apply and forms need to be easy to complete. Providers need to have suitable and competitively priced services and make these well known. They need to actively promote the possibilities seeking out referrers (office staff, MEE and caregivers, GPs, GPs, home carers) and making sure all concerned know the application process and who can help carers apply. They need to know that the services they can apply for to support them in their home can include volunteer services such as babysitting, visiting service, voluntary home help, replacement care services; or professional services with specialist babysitting for children with special, needs, supportive support, home support.

For outside the home these can include: day care facilities such as day care / treatment centres, night care, specialist day activity centre such as country/farms and meeting centres; or Multi-day facilities, such as lodging, host family, interval care, short-term survey, care hotel, care farm; or even custom/ tailored holidays, or family vacations in known and recognised centres; and recreational activities for the informal carer to attend without their loved one (e.g. multi-day care)

Financial support is a frequently reported problem is that of financial hardship. Caregivers may find that as a result of their changed role there is a considerable difference in their financial situation. This may in part be because their loved one can no longer contribute, or it may be that they have had to cut work hours down to meet their role as a carer. Whatever the cause there are measures that have been put in place to help those who suffer from financial problems, and this can include access to additional finances. In the Netherlands, financial compensation is possible through: direct tax compensation (extraordinary expenses); special welfare payments; and/or compensatory maintenance costs and home-living aids for disabled children. These personal budgets are described in principle, but it is not always clear that although described financial compensation, it is really a route that offers possibilities for helping to meet the additional costs that a career has to cover as they look after their loved one. This carer financial complementary financial scheme is organised and run by local government schemes, these are intended to support all caregivers who as they care for their loved ones need additional help but as with respite care these budgets vary across the country with every local government able to make its own policy. Thus in addition to yet another inequitable service based on a post code lottery, it is hard for carers to work out what their area can offer, or if they move why the entitlement has changed. This situation must be addressed urgently if carers are to be able to work out their entitlement and then receive the financial support they need.

The final need/function is **material help**. It is now generally accepted that in some instances to remain in the family home material adjustments must be made to the living and/or sleeping accommodation. These adaptations which may involve the installation of specialist equipment can be expensive and many families are unable to buy them for themselves. However, whilst in principle this is a praiseworthy scheme, as with other support the individual needs to complete a myriad of complex forms, then wait to be assessed, and if accepted wait for equipment to be fitted. This is the third area where decisions vary across the county with the local authorities choosing what they will sport and what they won't. It is extremely dispiriting for carers to work their way through the maze of information and bureaucracy only to find that in their area the very thing they need is not available. However, here again there are multiple forms to complete, and here again policies vary across the country. Needs should be judged on their merit not on where individuals reside an should include home accommodation adaptation, addition of formal car facilities, room for professional carers to help care provision, easy access/disability parking or adapted mobility vehicles, specialist tools such as lifting equipment and additional It facilities. The importance of this type of aid has to be stressed as this material aid primarily aimed at supporting care needs not only helps with care it may make the difference to an individual being able to stay in their own familiar environment/home.

While the spirit of the WMO (2007) was greater involvement by the community, and moving the responsibility for the community to take care of itself in some of the areas outlined here, it has led to confusion disparate and in some instances fragmented and inequitable care provision. The health care professional has been in the unenviable position of trying to find ways round the differences to try to equalise and standardise the services proffered.

2.4: Informal Caregiving

Informal care has always been a key element of family life. The need give the extra care to enable parents, children, parents, siblings and other relatives to remain within their own familiar home environment and social circle has always been accepted, on the whole without question. However, there are demographic and sociological changes in society that affect families at all levels, impacting on their ability to carry out the activities needed to fulfil their additional role. On the macro level, these include aging, family size, changes in employment roles with increasingly all adult members of a family unit needing to work, and in consequence having less time for them as a family unit to meet all their commitments.

In health care terms, the combination of the increased incidence of chronic disease, the high consumption of services by the increasingly ageing population, medical advances and financial constraints in service provision increases the amount of informal care that is needed. Until recently the importance of the role of the informal carer was not fully recognised with the result that the impact on the carers themselves is not assessed or considered when care planning. It is essential that their care contribution to society is recognised as only with appropriate adequate support can they continue to provide the care needed, especially with progressive diseases such as dementia where the burden of care increases exponentially with time.

Today, in politics and policy planning in the Netherlands, the role of the informal carer has finally been recognised, but there has been little research into what they need. The need for appropriate support for these essential informal carers is slowly gaining wider recognition, but it is taking too long to increase the support available to informal carers. An array of informal care support services has been initiated but carers are not always told it is there, or what support they are entitled to. There needs to be an explicit focus on the provision family care, and on developing and disseminating information regarding the support services available.

The local governments in the regions within the Netherlands which is known as Wet Maatschappelijke Ondersteuning (WMO) have the intention of involving the local people more developing a policy in supporting informal carers as it is written out In the WMO. Carers have to know what the options are in caring for a loved one and be supported in the care. There should be an explicit leaflet in which it is described what the support possibilities are in the community. It should make clear what is available and how and where to get it and what the conditions are for using the possible support. It should be clear from the information how the coordination is organised and in what way the cooperation between professional and informal carers will take place.

The support of informal carers is primarily the responsibility of the local government but always in cooperation with professional care providers and should include permanent consultation with the carer. The support must meet the needs of the carer at the moment they ask for help, knowing that the situation can change and with that so will the needs of the carer. The carer is at the centre of the support process and all other players such as professional care givers and the GP must focus on and meet the needs of the carer. With this as a starting point, every municipality has to develop a free resource that is easy to access either in paper or electronic format that is aimed at specifically at the informal carer. As the WMO documentation explicitly states that the carer is central to the process, the possibilities for support in each specific region should be included, together with the factors affecting its availability and accessibility.

2.5: Summary

The number of people with dementia in the Netherlands is now at the number where health services are stretched and the professionals are struggling to cope with the ever rising demand. This situation will continue as the population continues to age, and the incidence of dementia rises. With a predicted number of over 500,000 diagnosed patients within the next 25 years, informal carers will be increasingly expected to provide some if not all of the care (ref). Support systems must be developed, hence the urgent need for research into their perspective of the support they receive.

After all, it is the case that the government's policy is aimed at ensuring that citizens are increasingly responsible for caring for each other and that they only have access to professional care and support if self-care and informal care are inadequate. This fact, coupled with the strong growth in the number of people with dementia, means that the carers will play a much more important role in the near future. And that is only possible if the carers receive maximum and tailor-made support to continue to care for their loved one.

Their position must be improved and support possibilities must be expanded to enable informal carers to continue in their chosen role with their loved one with dementia for as long as possible. There is much to be found in the literature about the phenomenon of dementia, and in the Netherlands, quantifiable research has also been done among informal caregivers, to establish their backgrounds, their profiles and what if any support they receive. However, there is little available information regarding how they cope, what they need, what their own views of their role or even what they want for themselves, their family and their loved one. In the light of this absence of qualitative research, this study has focused on gathering rich, in-depth information from the carers themselves. A grounded theory approach has been used, because with its focus on consensus, and contemporaneous data collection and analysis it supported the aims of the study.

Chapter 3: Informal care in an international perspective, classification and treatment in the Netherlands

3.1: Introduction

On starting this study it was evident that there was a wealth of information on the importance of Informal Carers but not on what the informal carer needs are during this journey with their relative. This review following Aveyard's (2019) method was undertaken to retrieve primary research that would answer the research question The review analyses the findings where statistical QoL survey scores were used to assist interpretation of qualitative findings. Qualitative research is an established method of investigating the lived experience of illness that may not be captured by quantitative health data (Abbey et al., 2011).

3.1.1: Search Strategy

A number of electronic databases including Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, MEDLINE and EBSCOhost were searched for potential sources using keywords and a combination of search terms were used. A search of the reference lists of the literature identified yielded further articles for inclusion (Aveyard, 2019). Literature searches to support the study design and activities revealed two different types of literature firstly, regarding dementia as disease, its different forms and possible treatments, and secondly, information regarding the meaning of dementia for family and friends, carers, society and the professional care givers. It was evident that the major part of the Dutch literature was not focused on dementia as a disease but on the physiological impact and the medical care needed. There is no cure for this disease, hence the need for this study with its focus on the best care in daily life for the person with dementia, and support for their informal carer and family as a whole.

To address the research aims, primary literature was the main type of research used incorporating qualitative, quantitative and mixed method studies were used, as the different approaches can yield broader information and explore the research topic from varying perspectives (Ingham-Broomfield, 2016). Despite sitting low on the hierarchy of evidence pyramid (Polit and Beck, 2014), qualitative research seeks to understand the entirety of an experience including feelings and attitudes; an insight that would not be gained from quantitative data alone (Aveyard, 2014; Ryan et al., 2007). That being said, quantitative research can be used to verify the findings of a qualitative study (Aveyard, 2014). Moreover, mixing both methods enables strengths of each approach to be drawn upon and weaknesses to be overcome (Ingham-Broomfield, 2016).

Therefore, the articles included in this review are arguably exhaustive of the research literature available to inform the research. In addition to UK papers, articles have been included from the eight countries which are similarly developed with robust healthcare systems (United Nations Development Program, 2019). This together with the support of informal carers of patients with dementia, the practical management and issues of which are relatively universal, make inclusion of these international papers appropriate (Harris & Kuppurao, 2012). Following a review of the literature gathered it was possible to divide the evidence in to the following key sections, Informal care and dementia in The Netherlands, medical classification and physiology of Dementia and Treatments

3.2: Informal care and dementia in the Netherlands

There is more evidence about dementia and informal care in daily life within the Dutch literature, probably because one in three people from the Netherlands is, or has been a carer for their relatives. The Alzheimer Nederland foundation has developed a wealth of information and supportive literature for professionals as well as for carers. In addition, informal carers have now started writing books based on their own experience of living with a loved one with dementia (Buijssen 2012; Coene 2012; Dirkse 2011). The government (Sociaal Cultureel Planbureau (SCP), de Boer 2015) publishes information about informal carers, based on their survey research carried out bi-annually. Currently, the statistics indicate that there are more women (58%) than men (42%) who are informal carers, although the government data records few differences between their roles as carers. About 80% of the carers provide care within the close family unit, of this, 45% care for a parent, and 14% a partner, with 10% of the people with dementia needing constant attendance (cannot be alone longer than one hour and a half), 16% of carers care for a friend and 6% help neighbours. Of the 18-64-year old informal carers, five out of six are in paid work, with 25% working 32 hours or more per week. In the latest survey, only 7% of caregivers provide care and assistance on their own, while. 26% form part of a network with other caregivers and a further 26% are involved in a network of both informal and professional caregivers. For 8%, the care is supplemented by professionals, and 15% of assistance is provided to someone in a healthcare institution, where by definition, the care is shared with professionals. Of the remaining 18% responses regarding carers were not given (2015, de Klerk et al)

Collaboration with professional caregivers is not always successful: half of the informal carers think professionals do not decide appropriately the nature of the care needed, and over 50% of them stated that the professionals do not consider the needs of the informal carers themselves. Caregivers of people with dementia are among least satisfied with the cooperation they have with professional caregivers, with one in three reporting not daring to and /or feeling unable to ask for help and only one in five caregivers using any formal support. One in 10 caregivers reported finding it difficult to care for themselves, and an increasing number reported finding it difficult not to lose their patience with their loved one (de Klerk et al; 2015) Interestingly, few reported that money was an issue, but the overwhelming majority wanted support and appreciation, stating that the most important thing for them is the need for understanding and acceptance.

3.2.1: Informal care and dementia

Caring for someone with dementia, relatives stated it is very important to have good information, practical guidance and help with dementia, and for some this included wanting access to fellow carers for a listening ear, understanding and tips. Where no formal diagnosis has been made, there was considerable uncertainty and anxiety, they reported not wanted what they described as vague and 'fluffy' conversation. They want what they described as a "no fluff feeling" (Zorgstandaard dementie page 7), they know and feel that something is wrong but cannot tell what it is. For some, this phase of uncertainty lasts for many months, and occasionally well over a year. With the diagnosis, the explanation of the abnormal behaviour is suddenly clear. After diagnosis, which is often experienced as a shock, for many there is yet another period when nothing more happens.no specialised help is offered and the use of a professional case manager in dementia is raised. For some families a feeling of shame and stigma can cause inertia, while they all wait for something more to happen (Diefeldt 2014) Uncertainty with the type of care available, and support systems contributed to their feelings of no knowing which way to turn. The challenge for them is that this may well be the first time they have been in a situation where care is organised and offered by different elements of the health service, and they do not know about the many different solutions and many agencies that can help. Working out which is the most appropriate is difficult and time consuming, and for some, fear of wasting the professional's time stops them asking for help (Peeters et al 2012) an independent case manager in dementia can help make choices, and the GP should remain an important point of contact in care.

In the Dementia Care Standard (2013 Alzheimer Nederland en Vilans), important conditions are described for good dementia care. (See appendix 4)

3.3: Informal care and dementia in international perspective

To find more information and evidence of the situation in other European countries where publications have been made on dementia and carers, the following review of the literature was completed to understand if the same issues for informal carers are present internationally.

Following the Dementia Care Standard (2013 Alzheimer Nederland en Vilans), the subjects of the review are:

- Cost savings by substitution from professional to informal carers
- Looking for recognition: what is the position of the carers in care plans?
- Respite care: what types of respite care are available?
- Information for carers : what kind of information is available for carers and where does the information come from?

3.3.1: Costs

Because so many people deal with dementia, healthcare costs are high. Health care expenditure for dementia amounted to 9.1 billion euros in 2017. (RIVM 2017)
This corresponds to 10.3% of total health care expenditure in Dutch health care. This will be an estimated € 12 billion in 2030, and € 15.6 billion in 2040. This expected increase is partly due to the aging population. Research by the Social and Cultural Planning Bureau shows that informal carers in the Netherlands are currently already saving society about 6.6 billion euros per year (Visser et al 2013). This applies to all informal carers and therefore not only to the informal carers who care for a loved one with dementia. Yet this is a significant part of the total costs that are spent on total health care in the Netherlands. In fact, more than 7,5% of these costs. It is estimated that informal carers provide 4 to 5 times as many hours of care than total professional care.

It is worthwhile to look at European level at cost savings through substitution of professional care. The aim is always to keep the expenditure of professional care within limits by stimulating informal care. This concerns the care of people with dementia.

Bremer et al (2017) study involved looking at an empiric analysis based on data generated from the European project: Right Time Right Place. (P. Bremer et al. / Health Policy 121 (2017)

613–622) This survey was conducted in eight European countries. A distinction was made between the different types of care: the use of professional home care, the visits of a specialised nurse and the outpatient visits. A clear and demonstrable relationship has been found in this study between the use of informal carers and the professional commitment and the associated costs. However, it clearly depends on the type of professional care. The use of home care and nursing visits at home were reduced, but the number of outpatient visits increased. The costs of professional care deployment are reduced in all countries by more deployment of informal carers. the effects are different in the various countries.

It is essential to take into account that the relationships between the two types of care seem to differ within different countries. In Finland, France, Germany, Sweden and the Netherlands there is an established substitution relationship with regard to at least one of the home care services while no such relationship was observed in Estonia and Spain. (Bremer et al 2017) At first glance, these results seem to contradict the findings of Bolin et al (2008) who found further evidence for a north-south gradient by revealing that the negative effect of informal care on formal home care use was more apparent in Central and Northern Europe than in Southern Europe.

According to the authors of the article, this divide is indicative that in countries with a stronger family tie, informal care is replacing formal health care to a greater extent. A possible explanation for the lack of a substitute association between formal and informal care in Estonia and especially Spain which could be the fact that in these countries the use of formal health care is already quite low while the level of informal care is clearly above the European average. (Bremer et al 2017) Therefore, it could be assumed that in these countries the amount of formal care provided at home is already minimal and that this small amount is not affected by the amount of informal care. In addition, it should be taken into account that the majority of people with withdrawal will be admitted to a nursing home at some point, as their care needs can no longer be adequately met by carers. (Bremer et al 2017) However, choosing the right time to move people with dementia from their home to an institutional care facility is complex, as it requires extensive knowledge of the outcomes and benefits for both caregivers and patients (e.g., quality of life and quality of care) at home. care and the institutional setting. (Bremer et al 2017)

Many European governments stimulate the use of informal care with an aim to save the costs of professional care deployment. the expectation is that more informal care can replace professional care: a substitution (Bremer et al 2017) his expectation is correct, but the additional costs of using informal carers must be taken into account as these will partly compensate for the gross savings. (Johnson et al 2001) The reduction in the labour supply and the resulting loss of wages are a component of this. In addition, more use of informal care can also lead to overburdening and concomitant more use of health care by the carers themselves. In some countries such as Germany allowances are paid directly or indirectly to informal carers or some countries provide a reduction in tax. (Bremer et al 2017) The situation is therefore different in every country, whereby in a general sense the conclusion is justified that more use of informal care does have a cost-saving effect.(Bremer 2017)

3.3.2: Looking for recognition

The carers of a loved one with dementia need recognition and would like to be part of the care plan for their loved one. This could be in the home situation where the carer receives help from professional home care workers or in a nursing home. In the latter situation, carers do not feel less responsible for the care of their loved one with dementia. In international practice the degree of recognition is strongly influenced by the way in which professional care in a nursing home approaches the informal carer.(Boumans et al 2018).

What emerged was the attitude of the formal care provider with regard to informal carers who influence the improvement of informal care. Two mechanisms were found that explain which attitudes of formal carers can increase informal care provision: contact between formal and informal care providers and stimulating contact between residents and their carers.

Two studies (Hemingway et al., 2016; Moyle et al., 2013) have shown this. The informal care provided by family members to people with dementia in residential care facilities increased as contact between formal and informal caregivers increased. Stimulate the relationship between residents and the caregivers. To the frequency of informal care, examining two studies (Bigby et al., 2014; Palmer, 2013) that it is important that formal caregivers use the relationship between residents and their carers. Palmer (2013) discovered this after this relationship encouraged, caregivers brought favourite foods and personal items from home. They also planned or participated in activities that the person with dementia enjoyed. In this way informal caregivers became more involved with the life of the resident.

When recognizing the role of informal caregiver, a very welcoming attitude of formal caregiver towards informal carers is absolutely indispensable. (Bigby et al., 2014; Carr et al., 2011; Fetherstonhaugh et al., 2016; Milte et al., 2016; Raber et al., 2010; Scerri et al., 2015.

Recognition of the role of the caregiver as a facilitating element because it contributes to a change in the attitude of the formal caregiver and could thus indirectly contribute to the informal care provision. Formal carers should recognize the role of informal carers as a source of information about residents. (Fetherstonhaugh et al., 2016; Raber et al., 2010; Scerri et al, 2015). Families and significant others are often aware of the person's likes and dislikes; these can be useful in improving the relationship with residents and the personalization of their care (Fetherstonhaugh et al., 2016; Raber et al., 2010; Scerri et al, 2015). The more formal health care providers know about the resident, the more they can help in decision-making (Fetherstonhaugh et al., 2016).

Sometimes you can talk to the family and just search you know what their habits were like in the past there was not always enough water for it shower and they were not used to it showers. They would rather have bathed. (caretaker; Fetherstonhaugh et al., 2016, p. 218)

3.3.3: Respite care

Everyone needs a break. Respite care provides caregivers a temporary rest from caregiving, while the person with Alzheimer's continues to receive care in a safe environment. (Kruiswijlk et al 2016) Respite services can support and strengthen your ability to be a caregiver.

Providing respite to carers is seen as an important tool for support. The most recent development is the publication of the results of a task force set up by the Ministry of Health, Welfare and Sport (Clemence Ross C 2020) to study respite care in the Netherlands and improve it following recommendations. The results were published in a report at the beginning of 2020. the main conclusions at a glance:

- There is too much thinking in terms of supply and too little attention to the needs of the informal caregiver.
- Access to respite care in the social domain is insufficient. The cases show how difficult it is for informal carers to receive timely support. Access to respite care is a major bottleneck.
- The connection between the social domain and the healthcare domain is insufficient, bottlenecks are known and much discussed. That may seem like an advantage, but it is not if it is not perceived as sufficient that these can be changed in practice.

(Ross C, 2020)

The reasons for this are:

- Insufficient awareness of informal carers and respite care: the informal caregiver is not aware of the fact that he / she is an informal caregiver and municipalities and policymakers are insufficiently aware of the possibilities of respite care for the informal carer.
- The informal caregiver has no position. Within the various client streams of people in need of care (including dementia, mental health care, people with disabilities and youth), the informal caregiver is at best a derivative of the person he / she cares for.
- Solutions are complicated by the system discussion The obstacles to the proper use of respite care are attributed to the complexity of the regulations arising from the different laws.

(Ross C, 2020)

The following recommendations have been formulated from these conclusions:

- Access to respite care must be improved
- We need more focus on the needs of target groups
- Much is possible within the system, but has te be started
- The use of good examples in a variety of ways
- Reinforcement of respite care must be facilitated in practice
- Actions to continue strengthening respite care:
    - Research and evidence
    - Information provision
    - Improvement of respite care at local level

In order to gain insight into the actual situation and the developments surrounding respite care, a search was made in the available literature. The literature discusses the use of respite by carers of people with dementia (Neville et al 2015). This study provides an overview and comparison between the situation in Europe, the UK, Australasia, and the USA and Canada.

Respite care is seen as a cornerstone for caring for people with dementia at home and is used by caregivers to reduce stress related to care needs by giving them time to rest and do things for themselves. (Neville et al 2015). This maintains the nurturing relationship at home and possibly prevents long-term placement in an institution. Despite numerous anecdotal reports in support of respite care, caregiver admission of people with dementia remains relatively low. Neville et al (2014) examined the factors determining the use of respite by caregivers of people with dementia by looking at quantitative and qualitative research, mainly from the 1990s to 2012. Seventy-six international studies on different types of respite care were included for these review and their methods were critically reviewed. The main topics identified related to access to information, barriers for caregivers seeking respite need, satisfaction with respite care, including outcomes for caregivers and people with dementia, the characteristics of effective respite care and the role of health professionals in providing appropriate respite care. Finally, the limitations in considering the literature as a whole were highlighted and recommendations for future research were made.

Based on the current literature, it is a challenge to predict which caregivers will benefit from respite and the reasons why this may be (Mavall & Malmberg 2007). The challenge stems from the sheer diversity of all of the following:

- the people involved
- the nature of the services provided and
- the kind of research conducted so far

Characteristics of the caregivers and people with dementia vary in terms of their relationships, living situation, socioeconomic status, age, education, sources of support, role expectations, severity of disabilities, types of behavioural and psychological symptoms of dementia, physical health and reasons for seeking respite (Brodaty & Gresham 1992, Strang & Haughey 1998, Lee & Cameron 2004, Mavall & Malmberg 2007). Respite services differ in terms of availability, programs, hours of operation, convenience, staffing, staff training, and transportation. Different governments (countries and even states or provinces) differ in their funding levels and models for caregiver respite care. The survey itself varies in measured results, sample size, methodology, length of time, and even definitions of respite. As noted in part of the previous research, the outcome measures of interest, such as burden, may also be too complex, or influenced by too many factors, to be accurately assessed by current resources (Theis et al. al. 1994, Perry & Bontinen 2001, Mavall & Malmberg 2007).

As a result of the many confounding factors mentioned, as well as the sometimes contradictory results that are reported, definitive conclusions about the use of respite care by caregivers are difficult to make. Only a small number of experimental studies (RCTs) have been conducted in the area, so previous systematic literature reviews are limited in scope (Flint 1995, Acton & Kang 2001, Lee & Cameron 2004, Mason et al. 2007, Neville & Byrne 2007). Other ratings were topically or geographically limited (Tang et al. 2011). As a result, much valuable, significant, and relevant research was not covered in previous literature reviews.

The concept of respite used for this study was that presented by Chappell et al. (2001) who defined it as' a break, a temporary halt, or a rest ', seen as a' result 'rather than a' shift (p. 202).

The outcome can be seen as an "internal" experience in which caregivers take a break without removing themselves from the care situation or not seeing the need. Respite as an "external" experience occurs when there was some sort of separation from the care situation. When we examined the strengths and weaknesses of this concept in relation to the findings of the review, we found that, while current research focuses primarily on the provision of respite care, many of the outcome measures relate to caregivers and people with dementia. as opposed to the services themselves, i.e. type and frequency of services used. We found evidence to support the concept of respite and that internal and external respite processes can mutually benefit each other for better health outcomes for caregivers and people with dementia.

Insufficient access to information or too much information and limited referrals by doctors were some of the reasons identified for the poor use of respite services. (Chappell et al, 2001) Better use of respite can come about by improving people's experience of using internal respite by accessing counsellors or support groups to help identify and implement strategies that make the most of stolen moments, due to the importance of care delivery and enjoy periods of anxiety-free care. Those seeking external forbearance options may require a thorough assessment of their actual needs and the provision of need-specific forbearance services (informal or formal). Providing information along these lines would streamline the experience of both caregivers and health professionals to build their confidence to be more proactive in receiving and granting respite. The idea of internal respite is certainly supported by outcomes identified in the research literature. Brodaty et al. (2005), Cox (1997), Braithwaite (1998) and found that caregivers often claimed that respite was not necessary or that they had made arrangements with family and friends. Despite this, health professionals should be aware of the stoicism often displayed by caregivers or that they are unaware of the insidious effects of physical and emotional exhaustion and the possibility that caregivers will only seek reprieve if it was a long time ago (Larkin & Hopcroft 1993, Brodaty et al. 2005). One aspect identified in the literature that is not directly addressed in Chappell et al. (2001) 's concept of respite is how to deal with the negative connotations associated with respite. Due to the degenerative nature of dementia and the fact that many carers, especially spouses, are elderly, respite care is required. Overcoming the feelings of guilt and failure and negative social attitudes of caregivers may require recognition of the benefits of respite for the caregiver and also for the person with dementia (Beisecker et al. al. 1996). Respite, whether internal or external, should be a positive experience for both the caregiver and the person with dementia. For example, it can be designed to be person-centered, dementia-specific, culturally specific, and / or age-related (Parahoo et al. 2002, Phillipson & Jones 2011a, 2012).

Respite needs can be cyclical, with internal respite benefiting from external respite and vice versa. The evaluation found that the use of external respite services gives caregivers time for self-care; it gives them relief from the caring role, and respite services can be proactive in ensuring the comfort and safety of the person with dementia so that the caregiver does not have to worry (Beisecker et al. 1996, Perry & Bontinen 2001, Stockwell-Smith et al. 2010). This relief can enhance the coping mechanisms for internal respite and, consequently, reduce the need for external respite. However, the potential for respite can only be realized if it is conceptualized from what caregivers perceive to be effective respite for them and the person they care for (Chappell et al. 2001).

This review has shown that by taking a broader view, a more complete picture of the current evidence on the topic is possible. For example, a much better understanding of the role of respite in the life of the caregiver can be obtained by interviewing caregivers (either in a structured or more in-depth manner), rather than through strictly controlled interventions. If specific interventions were tested, those studies could benefit from looking for innovative ways to control confounding variables, for example by using randomized cluster studies (for example at the level of a community or specific service). Other methodological factors to consider (as recommended in previous reviews) include sample size (Neville & Byrne 2007), lack of explicit definitions of the type of respite and forbearance studied, and unspecified inclusion / exclusion criteria for participants (Flint 1995, Lee & Cameron 2004). While some authors preferred to address different types of respite separately (Lee & Cameron 2004, Phillipson & Jones 2011a, b, 2012), others convincingly argued that a broader approach would better serve to understand how respite services can provide the needs of individual caregivers (Flint 1995).

3.3.4: Information for carers

Whether it concerns respite care or recognition; time and again, the information provided to carers determines the position and support that carers need and receive. The international literature on this subject contains a large amount of information that indicates that information should be tailored and individually provided to carers of people with dementia. Thompson et al (2007) investigated whether information and support interventions improve the quality of life of people caring for someone with dementia. The outcome is that there is little evidence that interventions aimed at supporting and / or informing caregivers of people with dementia are uniformly effective. There is however a difference between individual-based interventions and group-based interventions. The group-oriented information provision to carers seems to have a positive effect on depression in particular.

Mc Kechnie et al (2014) mixed-methods study examined the impact of a well-respected UK-based online support forum for carers of people with dementia. The participants in the interview reported a series of positive experiences and benefits of using the Internet forum. Limited negative experiences were also reported. Many of the reported experiences and benefits are unique to online peer support.

Zwaanswijk et al (2010) in their study ‘Problems and wishes of informal caregivers of people with dementia: a comparison between the initial phase and later stages in the disease process for a longer period of time’, examined whether caregivers of people who have symptoms of dementia for less than one year differ from carers of people who have been showing these symptoms for a longer period of time. It looked at the differences in perceived problems, the use of outpatient forms of professional support and the need for additional professional support. The results are based on a questionnaire survey of 1,494 caregivers. Almost all informal carers experience problems caring for their loved one, regardless of the phase of the dementia process. Informal carers especially have difficulty with changes in their loved one's behaviour and dread admission of the person to a care institution. Informal carers of people who show symptoms of dementia for a longer period of time (> 1 year) also experience limitations in their social network. Most people with dementia receive some form of professional support. Nevertheless, the majority of informal caregivers need additional professional support, especially in the form of advice and information. It is therefore not desirable to limit the options for support for people with early dementia symptoms and their informal carers. Given the need for additional support in the initial and later stages of dementia, people with dementia and their caregivers must be supported throughout the disease process.

The 'Care standard for dementia' (Alzheimer Nederland 2013) states: The aim of the information, information and support is to motivate people to seek help on their own (push). In addition, better recognition of dementia in the "gut phase", both by the person with dementia and their loved ones and by care and social workers who come into contact with people in the "gutsy phase", taboo reduction, faster diagnoses and referrals is a goal. This concerns public-wide information, for example via TV campaigns and by social and health care organisations: accessible information and communication about dementia, embedded in general information and education.

3.4: Classification of dementia

The following section was utilised within a formal leaflet that was given to the informal carers of patients with dementia as a number of research participants requested further physiological and treatment information in order for them to understand the process more effectively.

This section is aimed to distinguish information specific to medical diagnosis and treatment, from information regarding symptom management and caregiver strategies, such as triggers, sources, barriers, and expectations. This is not a construct that most informal carers consider. However, the distinction between medical and caregiving information needs to be clarified.

Dementia is the umbrella term used for a combination of symptoms (a syndrome), where the neurological function is such that an individual is unable to complete the processing of information, and encompasses over fifty different variants each with their own physical and psychological presentation. The most common forms of dementia are Alzheimer's disease, vascular dementia, frontotemporal dementia (FTD), Lewy body dementia and Korsakov syndrome. Due to the differing disease trajectories, it is essential that the correct diagnosis is made and that the carer has the information on which an estimate can be made of the manifestation (s) and the course of the disease over time. Of the multiple types of dementia, with differing presentations, physiology and disease trajectories, the most common are:

3.4.1: Alzheimer's disease (AD)

Alzheimer's disease (AD) is the most prevalent cause of dementia and represents a growing problem within the aging population. The International Alzheimer's Disease Report estimates that 47 million people worldwide are living with AD in 2015, and this is estimated to increase to 131 million people by 2050 (Baumgart et all 2015). This is the most common form of dementia as almost 70% of people with dementia have Alzheimer's disease and tends to present initially with memory problems. As the disease gets worse the individual has trouble remembering and completing everyday tasks.

Research has shown that an increase in protein within the brain cells is a potential cause of AD. (Tramutola et al 2017). The brain is particularly vulnerable to oxidative stress, and accumulation of oxidative damage may lead to an altered redox balance and a reduced ability of antioxidant and degradative systems to eliminate oxidised/ misfolded proteins. (Tiwari and Patel 2014). Perturbation of the redox homeostasis may in turn exacerbate Reactive Oxygen Species (ROS) production that may result in the modification of several intracellular targets, including nucleicacids, lipids and proteins. In particular, redox proteomics studies have been a powerful tool to analyse the impact of protein oxidative modifications on protein function. (Aluise et al 2011). This approach allows the identifying of proteins that are increasingly oxidised in pathological conditions and how these irreversible modifications translate into clinical signs of AD. A number of oxidatively modified brain proteins have been identified using redox proteomics in AD; this suggests that there is an alteration of a number of biochemical and cellular processes such as energy metabolism, protein degradation, synaptic function, neuritic growth, neurotransmission, cellular defence system and long-term potentiation involving information and memory.

This suggests that impairment of brain function due to protein metabolism is a crucial event found in the early stage of AD, this is secondary to the oxidative stress and also shows a decreased ATP production which leads to an impairment of AdenoTriphosphate (ATP) dependent processes where all cellular functions are involved. This highlights that reduced glucose utilisation, mitochondrial deficit and a decreased production of ATP are early AD associated events that may contribute to the neurodegenerative process and its progression that culminates in the development of Alzheimer's disease.

3.4.1.1: Symptoms of Alzheimer disease

Due to its pathology, a patient with Alzheimer has trouble with everyday tasks, making plans, and making decisions and as it progresses, processing information from conversations. For some there may also be behaviour changes with families reporting they have 'changed' in character. For example, they may exhibit signs of restlessness, increased suspicion of others, aggression or listlessness. They can develop rapid mood swings, and new or vital information becomes hard to recall and is ultimately lost. Finally, long term memory begins to fail and orientation to place and time becomes increasingly difficult culminating in an inability to remember where they are, or which day, which month, or what year it is.

Aphasia develops limiting communication, and where patients have been using a second language, this can be lost, further restricting their ability to relate to, and interact with family and friends (Koedam et all 2010). While at the same time the onset of agnosia further inhibits their ability to participate in family life and activities, and this with increasing apraxia can in turn increase their sense of frustration and distress, adversely impacting on their behaviour patterns as they try to remember what was for them, an everyday part of life (Koedam et al 2010).

3.4.2: Vascular dementia. (Kapasi 2016)

Vascular dementia is one of the most common causes of dementia after Alzheimer's disease, causing around 15% of cases. (O'Brien and Thomas 2015) Neuropathological features of AD are the deposition of hyperphosphorylated tau proteins forming paired helical filaments in neurons called neurofibrillary tangles (NFTs), and the extracellular accumulation of amyloid beta (Aβ) in plaques. Hyperphosphorylated tau filaments are also commonly present in neurites, known as neuropil threads, and in neurites-associated within neuritic plaques (Spillantinni and Goedeart 2013). Although these pathologies accumulate throughout the clinical stages of dementia, they can also be observed in abundance in the aging brain of persons without any cognitive impairment. The contribution of vascular disease to the dementia pathological process, clinical expression and progression of dementia is a complicated and varied one.

Vascular pathologies such as, micro infarcts, micro bleeds, and white matter changes add to the likelihood of expressing dementia pathology and all contribute to cognitive impairment. This leads to people with dementia having disorders such as supra nuclear cerebral palsy (De Reuck et al 2016). Although there is evidence that atherosclerosis and impairment of the blood flow to the brain may contribute to the dementia process, whether these processes and pathologies initiate or accelerate the process of the disease progression remains incompletely understood. Overall, it is clear vascular and dementia pathologies rarely occur in isolation, and that the entity as a whole is classed as dementia. By targeting the vascular component, it may be possible to reduce the risk of developing dementia, and potentially decelerate the pathological progression of the disease. Many people with vascular dementia have cardiovascular disease and/ or other cardiovascular morbidities (Kapasi 2016) such as long-term high blood pressure, cardiac arrhythmias, diabetes and TIAs (short-term closure of a blood vessel in the brain). It is also possible that an individual will have had one or more cerebral vascular accidents (CVA) prior to being diagnosed with dementia.

3.4.2.1: Symptoms of vascular dementia

Cognitive changes in vascular dementia are much more variable than in other disorders such as Alzheimer's disease, and are highly dependent on the neural substrates affected by the vascular pathology (O'Brien and Thomas 2015). Due to the subcortical vascular pathology frequently interrupting frontal striatal circuits, predominant deficits in attention, information processing, and executive function are seen within these patients. Standard screening tests for dementia, such as the mini-mental state examination which was devised to detect Alzheimer’s disease might prove less sensitive to impairments, especially in these characteristic deficits. Other tests that highlight attention and executive function, such as the Montreal cognitive assessment scale or the vascular dementia assessment scale (VADAS-cog) are more likely to pick up deficits in this population. Other functions such as memory, language, and praxis are much more variably affected in vascular dementia and as with other dementias; non cognitive features are frequent and can be particularly distressing for both the patient and their family. Community studies (O’Brien and Thomas 2015) have shown a substantial overlap in neuropsychiatric features between Alzheimer’s disease and vascular dementia, with a very high burden of all symptoms in both subtypes although some symptoms, particularly depression and apathy, are particularly prominent in those with vascular dementia, and other features such as delusions and hallucinations are less frequent. What symptoms a person has with vascular dementia depends on the area of the brain that has been affected or damaged, as there are different types of vascular dementia. People who are diagnosed with vascular dementia tend to think, speak and act more slowly than those diagnosed with AD and they can find it more difficult to concentrate on tasks. In addition to mental decline, someone can also have physical manifestations, such as paralysis, muscle stiffening or a feeling of loss may occur.

3.4.3: Frontotemporal Dementia: presentation and symptoms

This form of dementia is known for over a decade. Frontotemporal dementia (FTD) is a focal clinical syndrome characterised by profound changes in personality and social conduct and associated with circumscribed degeneration of the prefrontal and anterior temporal cortex (Neary at all 2005). Clinical onset is typically in the middle years of life and the survival rate is about 8 years (Neary at all 2005). The presence of microtubule associated protein tau based pathological features in some patients and the discovery, in some familial cases, of mutations in the tau gene links FTD to other forms of tauopathy, such as progressive supranuclear palsy and corticobasal degeneration. However, more than half of all patients with FTD, including some with a strong family history, show no apparent abnormality in the tau gene or protein, indicating pathological and aetiological heterogeneity (Neary at all 2005).

FTD provides a challenge both for clinical management and for theoretical understanding of its neurobiological substrate and often occurs at a younger age. However, more than half of all patients with FTD, including some with a strong family history, show no apparent abnormality in the tau gene or protein, indicating pathological and aetiological heterogeneity. This condition is also known as Pick's disease. Changes in behaviour usually occur, but language and speech can also be affected. This form of dementia is caused by the death of brain cells in the frontal lobe (behavioural area) and/or the temporal lobe (language area). This impacts on decision making and coordination, emotional responses and language proficiency. The first manifestations of frontotemporal dementia depend on the place in the brain that is affected, but can lead to changes in behaviour, personality and speech and only at a later stage do people with frontotemporal dementia develop further memory problems. There are three variations of frontotemporal disorders determined by the first symptoms that occur, **Behavioural FTD** starts with changes behaviour, personality, emotions, and assessment of situations. **Language variation of FTD begins with** problems in language proficiency, including progressive difficulty in speaking, understanding, reading and writing. It is primarily referred to as progressive aphasia or semantic dementia. Thirdly, **Movement Variation of FTD:** is characterised by changes in motor skills, difficulty with movement, such as vibration, difficulty walking, frequent falls and coordination problems. It is also referred to as corticobasal syndrome (Neary at all 2005)

3.4.4: Lewy body dementia: presentation and symptoms

The broad importance of dementia is undisputed, with Alzheimer's disease justifiably getting the most attention. However, dementia with Lewy bodies and Parkinson's disease dementia, now called Lewy body dementias, are the second most common type of degenerative dementia in patients older than 65 years (Walker et al 2015). Despite this, Lewy body dementias receive little attention and patients are often misdiagnosed, leading to incorrect management of their condition. Over the last decade, considerable effort has gone into improving diagnostic accuracy by refining diagnostic criteria and using imaging and other biomarkers (Walker et al 2015). Dementia with Lewy bodies and Parkinson's disease dementia share the same pathophysiology, and effective treatments will depend not only on successful treatment of symptoms but also on targeting the pathological mechanisms of disease, ideally, before symptoms and clinical signs develop. The Lewy body dementia (LBD) is recognised by fluctuations in an individual’s mental decline and they often have symptoms of Parkinson's disease presenting with trembling of body parts like hands, stiffness in their muscles and joints, slow motion, a curved posture and a change in gait pattern when walking.

The mental deterioration of someone with Lewy body dementia can vary greatly from day to day. Many people with Lewy body dementia are regularly confused and they may also have other phenomena, such as depression or delusions. The phenomena of Parkinsonism can also vary greatly. In Lewy body dementia, there are Lewy bodies in the brain's nerve cells (Walker et al 2015). These are special protein deposits that originate when a brain cell is at risk, due to trauma or if there is a toxic substance present. In Lewy body dementia, the abnormalities are predominantly in the cerebral cortex, so Lewy body dementia is not inherited in the vast majority of cases.

Lewy bodies are also present in Parkinson's disease. In Parkinson's, these are mainly in the substantia nigra, an area in the midbrain where movements are controlled. The difference between Lewy body dementia and Parkinsonism is that when someone gets any dementia symptoms within one year after receiving a Parkinson's disease diagnosis, the Lewy body is called dementia. If a patient gets any symptoms of dementia later in the course of their Parkinson's disease, then this is classified as part of the Parkinson’s disease. Lewy body dementia resembles AD and Parkinson’s. This often causes an incorrect diagnosis in the beginning as the drugs for people with Parkinsonism have minimal effect on people with Lewy body dementia. It is therefore important that the diagnosis of Lewy body dementia is made as early as possible.

Someone with Lewy body dementia does not initially have memory problems or have trouble performing actions. These patients usually present with visual hallucinations as they see things that are not there. This makes it more difficult to recognise this form of dementia. An additional problem is that people with Lewy body dementia are often very sensitive to the side effects of the medication against hallucinations.

3.4.5: Korsakov’s syndrome: presentation and symptoms

This illness is not known officially as a form of dementia (Ridley et al 2013). The characteristics of dementia relating to excessive alcohol use have received increased research interest in recent times (Ridley et al 2013). Neuropathological and imaging studies suggest that excessive and prolonged use of alcohol may lead to structural and functional damage that is permanent in nature; however, there is debate about the relative contributions of the direct toxic effect of alcohol known as neurotoxicity hypothesis, and the impact of thiamine deficiency, to lasting damage. Investigation of alcohol related cognitive impairment has been further complicated by differing definitions of patterns of alcohol use and associated lifestyle factors related to the abuse of alcohol. Present diagnostic systems identify two main syndromes of alcohol-related cognitive impairment alcohol related dementia (ARD) and Wernicke-Korsakoff syndrome (WKS). However, ‘alcohol related brain damage’ is increasingly used as an umbrella term to encompass the heterogeneity of these disorders. It is unclear what level of drinking may pose a risk for the development of brain damage or, in fact, whether lower levels of alcohol may protect against other forms of dementia (Ridley et al 2013).

Epidemiological studies suggest that individuals with ARD typically have a younger age of onset than those with other forms of dementia, are more likely to be male, and often are socially isolated (Ridley et al 2013). The cognitive profile of ARD appears to involve both cortical and subcortical pathology, and deficits are most frequently observed on tasks of visuospatial function as well as memory and executive tasks. The WKS appears more heterogeneous in nature than originally documented, and deficits on executive tasks commonly are reported in conjunction with characteristic memory deficits. Individuals with alcohol-related disorders have the potential to at least partially recover both structurally and functionally if abstinence from drinking alcohol is maintained.

It is caused by a severe deficiency of vitamin B1, needed for the heart muscle function and the nervous system and cerebral functioning. In the Netherlands, the disease occurs mainly in people addicted to alcohol and as a result of self-neglect, poor diet or simply not eating. Korsakov syndrome is identified through the following symptoms. Memory Loss, with recent memory more acutely affected. Also, challenges with time and place, including placing events in chronological order and difficulty in orientating themselves to time and place. Patients with Korsakov's syndrome will often recognise their memory problems, and fill the gaps in their memory with fantasy stories. Known as "confabulating", or a "fair lie" because the individual with Korsakov syndrome will be convinced that they are telling the truth. The loss of memory in problem situations can lead to feelings of insecurity. Behaviour patterns can vary, with some patients becoming withdrawn, no longer initiating social contacts, while can become aggressive.

3.5: Diagnosis and treatment of dementia in the Netherlands

In the Netherlands, dementia is a clinical diagnosis traditionally made by GPs or for a few, through referral to a medical specialist (Prins et al 2016) there have been problems with this approach, with studies revealing the challenges GPs report when trying to diagnose dementia, these include, lack of time, uncertainty, inadequate payment models (when payment only accompanies a formal diagnosis), therapeutic nihilism (‘nothing can be done’), and the fear of stigmatising patients through application of a dementia diagnosis (Prins et al 2016). As a result, GPs currently appear to carry out a ‘watchful waiting process’ with those presenting with symptoms suggestive of dementia. Also dementia appears to be under-diagnosed with an estimated 50% of primary care patients aged less than 65 years not being diagnosed by their

GPs, even when symptoms clearly suggest dementia (Cornett and Hall 2008). Although therapeutic interventions to stop or slow the course of dementia have proven disappointing, a timely diagnosis of dementia is necessary to support patients and families from the early stages of disease onwards. Once the diagnosis is made, support can be offered to enable all concerned to start to comprehend the nature of the diagnosis and participate in the planning of care.

The NHG Standard Dementia provides guidelines for identifying dementia, diagnosing suspected dementia, and counselling and treating patients with dementia and their family. At least 20,000 people are diagnosed with dementia in the Netherlands every year with a considerable number of elderly people are living with dementia without knowing (Moll van Charante et al 2012). The prevalence of dementia in general practice has increased from 1.4% in 2002 to 1.7% in 2008. This means that a general practice with 2350 patients has around 40 dementia patients. The incidence is around two per 1,000 patients per year and increases sharply with age. Population screening shows no clear difference in age-specific prevalence between men and women. An estimated 3% of patients over the age of 65 are of immigrant origin. Increasing age is the most important predisposing factor (Moll van Charante et al 2012).

The latest revision (the third in recent years), of the Dutch College of GPs (Nederlands Huisartsen Genootschap 2012) practice guidelines on ‘Dementia’ provides more detail on how to decide whom to refer for further diagnostic work-up; for example, patients aged less than 65 years or with unusual forms of cognitive decline. Patients with a more typical presentation of Alzheimer’s disease and vascular dementia may still be diagnosed by their own GP Dementia (Moll van Charante et al 2012). This is different from the UK where the National Institute for Health and Care Excellence guidelines (2018) advise on further specialised diagnostic testing, including cerebral imaging, to exclude other cerebral pathologies and to help establish the subtype diagnosis. In addition to ‘disease diagnostics’, the Dutch guideline recommends ‘care diagnostics’, also remain based with the GP, who creates an overview of all care needs and initiates care when required. Thus, a care diagnosis can take place without a formal dementia diagnosis. However, the GP’s practice guideline on Dementia (Moll van Charante et al 2012) contain key statements that impact on the diagnosis and treatment of dementia in the Netherlands. These include offering diagnostic tests to any patient who exhibits signs of dementia. It re-affirms that dementia can be diagnosed by the GP or if the GP is uncertain, the patient can now be referred to a specialist. If no clinical abnormalities are found in and additional specific examination by the general practitioner, a referral for routine imaging is not seen as useful. The inclusion of multiple psychosocial interventions in care plans, can have positive effects on patients and caregivers, and help to reduce admission to a nursing home. All primary care needs to be coordinated in cooperation with local social care providers.

(Moll van Charante et al 2012) give four steps to assist in the diagnosis of dementia, three concerned with disease diagnostics and one with care diagnostics. These are the formal steps that all GPs should follow

1. The first step is to add to all consultations checks to assess for signs and symptoms of dementia, as it is recognised that patients often request for help for themselves, and observations. Concerns from family members should be addressed.
2. The second step is to complete a syndrome diagnosis based on the DSM-IV criteria for "dementia not otherwise specified". This includes assessing whether the individual has a memory disorder or further cognitive impairment(s) in language (aphasia), focused action (apraxia), recognition (agnosia), executive functions (such as planning, organising, consecutive action, abstraction); and disorders that result in a significant limitation in social or professional functioning compared to the previous level of functioning and there is no delirium.
3. In step three, a formal assessment should be made as to whether a referral for specialist assessment is necessary before a diagnosis can be made. The GP should include an examination to seek out signs and symptoms of reversible or less common causes of dementia.
4. The fourth and final step is to formally map out the required care and treatment for the patient and caregiver. In the case of the disease and care diagnostics, cooperation with other care providers such as practice assistants, district nurses, psychologists, case managers and specialists are desirable.

Cautionary notes included state that the prescription of cholinesterase inhibitors or memantine by the GP is not recommended. Also that A patient with dementia must be assessed by the Centraal Bureau Rijvaardigheden for suitability for driving a motor vehicle

The final section in the revised GP policy advises on the need for counselling for the patient with dementia and their family. It points out that the resilience of relatives largely determines how long patients with dementia can stay at home, and describes the importance of the use of appropriate interventions, including accessible, standardised information and occupational therapy, as part of the repertoire that can be used to support the patient and their family (Moll van Charante et al 2012).

In the light of the lack of accurate diagnosis by GPs (Prins et al 2016), as a final aide memoire, a short list of pre-disposing factors for dementia has been included. The list includes risk factors for other diseases, cardiovascular diseases such as hypertension, dyslipidaemia, diabetes mellitus, obesity and smoking, and how these can impact on dementia. Parkinson's disease is fully discussed, with a statement that half to three quarters of these patients will develop dementia, with the risk increasing with increasing age, and the length of time since diagnosis. Genetic factors are also fully discussed as these play a prominent role in people with learning difficulties, for example those with Down's syndrome where dementia can occur at a much younger age. They have also included factors with a less clear association with dementia, for example general decline or hospitalisation, depression, abnormal thyroid function, vitamin B12 deficiency, alcohol and oestrogen use (Prins et al 2016).

The guidance does point out that only modest preventative contributions can be made to maintaining cognitive functions, but argues that treating high blood pressure may be beneficial for preventing or delaying dementia. Increasing physical activity, especially for the elderly with an inactive lifestyle, appears to have a beneficial but minor effect. However, there is no evidence that lowering the homocysteine content by vitamins B6, B12 and / or folic acid, stricter treatment of type 2 diabetes and lowering cholesterol with statins is effective to prevent dementia.

Following publication of the guidelines, a training programme for general practitioners and practice assistants has been instituted, and access to specialised centres for diagnostics has been facilitated. Their advice is that the different components of the diagnostic tests should be divided into several sections each with its own contact points. However, in addition, the GP has to formally exclude other causes of cognitive impairment and carefully document all possible signs of dementia during the history taking, physical examination and any additional examinations. The GP also has to formally record the perspective of the primary care giver in order a full life and illness history for each patient, to maximise insight and information. A home visit can be used to add additional information about daily functioning and behaviour. (Gorissen 2009)

3.6: Diagnosis in the community

There are also now clear guidelines for GPs to expand assessment where there is cognitive decline in the patient, as recent Dutch statistics indicate that orientation, recognition, language and praxis disorders tend to be missed during the diagnostic assessments (Prins 2016). Assessment now includes checks for any symptoms of delirium, and consider issues surrounding awareness of their environment and concentration. They need to search for visual and auditory hallucinations, and signs of a depressive state. Other checks should be made to exclude other psychiatric conditions such as alcohol addiction or psychosis, which can impact on dementia; or any medication have to be checked. It is suggested that any medication with anticholinergic effects and benzodiazepines should be changed. Finally, the guidelines now state that it is important to involve the caregiver in this phase of the diagnostic process, and their perspectives included.

The general practitioner (or practice assistant) performs an MMSE and clock tick test in all cases of suspected dementia. The Mini Mental State Examination (MMSE) measures orientation, imprinting, short-term memory, language, recognition and visual construction. It is seen as a suitable scale for rapid diagnosis of cognitive dysfunction as it takes only around 10 minutes. Cherbuin’s (2008) systematic review found a sensitivity of 80% and a specificity of 86% for dementia, but noted that the number of errors on the MMSE increases with higher age, lower education level and poorer language proficiency. Thus, the score of the MMSE alone is not enough for the diagnosis of dementia. Patients with a high educational level or Parkinson's disease can still suffer from dementia despite (almost) optimal MMSE scores. The limitation that executive functions are little measured with this instrument have been known for over forty years (Folstein 1975, Tombaugh 1992]. Nevertheless, it is still in active use, and alternative cognitive tests are currently not recommended partly because of lack of evidence indicating their advantage over the MMSE and GPs are used to using MMSE.

In research settings, a score of 21 to 26 is associated with mild dementia, 10 to 20 with moderate dementia, and a score of 10 or less with severe dementia. However, the test is less reliable for non-Dutch speakers and where there is low literacy. The GP clock tick test, entails the patient drawing a circle, then adding the numbers of a clock to it, and setting the clock hands to 10 past 11. It measures some cognitive skills, including some executive functions, and is usually easy to perform regardless of literacy.

To complete the diagnosis of dementia, there has to be a series of consultations, with the guidelines pointing out that assessment of symptoms based solely on heteroanamnesis can be misleading. If the general practitioner has indications of dementia based on the (hetero) history and / or physical examination, but the scores of the MMSE and the clock tick test are normal, a full repeat assessment should be carried out following a further consultation. Dementia can be formally diagnosed if there are disorders of the memory, evidenced by the (hetero) case history and / or MMSE; and disorders of one or more other cognitive functions, as evidenced by the history and / or physical examination and / or MMSE and / or clock tick test; and there is a reduction in social or daily functioning due to memory impairment or other cognitive impairment (s), evidenced by the (hetero) case history, home visit or possibly decreased (I) ADL questionnaire.

3.7: Medicinal Treatment guidelines

In the Netherlands, a standard drug treatment guide NHG is used (Standaard dementia NHG). This makes a clear distinction between cholinesterase inhibitors, memantine, and other medication. The working group does not recommend the prescribing cholinesterase inhibitors and memantine by general practitioners. The guidelines state that the balance between effectiveness and safety is such that no predominant benefit can be expected. Therefore, if the patient and family want to explore the possibilities of a trial treatment with these, a referral needs to be made to a specialist centre.

Cholinesterase inhibitors (rivastigmine and galantamine) can show a slight temporary stabilisation in cognition, ADL or clinical functioning in some patients with mild to moderate Alzheimer's disease. However, overall research to date has shown minimal gains on the assessment scales used, and there are considerable methodological limitation in the studies conducted leading to little evidence of clinical relevance (Reisberg et al 2003) Similar criticisms have been made regarding research into the use of the glutamate receptor antagonist memantine in patients with moderate to severe Alzheimer's disease (Reisberg et al 2003) The effects of cholinesterase inhibitors in Lewy-Body dementia and dementia in Parkinson's disease appear to be positive, but again there have been few studies, and those that exist in the Netherlands are with small groups (Wang et al 2014) Evidence regarding side effects is still accruing, with few side effects reported in users of memantine, while with the use of cholinesterase inhibitors, gastrointestinal side effects such as nausea, vomiting and diarrhoea, also fainting, cardiac arrhythmia and cardiac disturbance have been reported. Following falls and/or faints hip fractures have been reported as being more common.

The guidelines point out that treatment of hypertension or hypercholesterolaemia does not affect the course of dementia, and that prescribing acetylsalicylic acid as a treatment for dementia is not useful.

3.8: Summary

In this study, the emphasis is not on researching the diseases or treating the diseases that lead to dementia, but entirely on the support of the informal carer and development of the service delivery and support that they can access. The evidence in the literature highlights this issue and it shows concerns regarding the position of the informal carer within the wider family unit but there is minimal literature investigating the position of the carer of an individual who has been diagnosed with dementia. However, the carers of people with dementia belong to the group people who are heavily burdened due to the complexity of the care of this client group. The Dutch government have made steps regarding the support for carers of people with dementia, through the publication of the 'Dementia Cares Standard (2013) but this is only a token gesture in the lives of the informal carer.

Chapter 4: Method

4.1: Introduction

This chapter outlines the research method used for this study. The choice of research design was based on the questions asked to address the study aim as these determined the approach needed for the research. There is much information about dementia and there is knowledge about family carers but the need of knowledge about the combination of these two aspects, badly needed for policy makers to improve the position of carers for their loved ones with dementia became the start of the research. The research design provides a framework for the whole study, including collection and analysis of data, sample to be used and ethical issues linked to the specific choice of method.

4.2: Research aims

The aims of this research project, were:

- To gain insight into the motives for caring, and the needs and wishes of (family) carers who are caring for a loved one with dementia
- To develop a conceptual framework and model that would accept that the family unit and not just the individual needed to be the focus for care.
- To make recommendations for policy and practice

Using these overall aims, two questions were formulated:

- What are the lived experiences of carers who are caring for a loved one with dementia?
- What do (key) carers of a loved one with dementia need in terms of services and support to be able to stay as key carers for as long as they wish to?

4.3: Study design: Identifying an inquiry paradigm and choice of method

The aims and the two questions developed from them, made it clear that the study needed to be exploratory, to try to gain insights into what it actually means to for a relative to care for a loved one with dementia and the impact that this type of caring has on their own lives by ascertaining how well (or not) they thought they were coping. How they saw their own need for support, how this impacted on their ability to care and, where appropriate whether they were able to share the caring with others. The findings from the exploration needed to be in a format that could be used to develop the needed conceptual framework, and, could also be applied in practice to identify strategies to empower the carer and facilitate self-development and the identification and implementation of tailor made support mechanisms.

In the Netherlands today, as stated previously, my professional experience has shown that the limited time and input for the family/ informal carer has a major impact on the care they can deliver and maintain. In a situation where carers have to care for individuals who, as a result of their dementia cannot always speak for themselves, the carers should as of right, have a leading position in making choices for care, welfare and living. Yet it seemed that few organisations have policies which automatically place the carer in the centre of planning, instead using standard procedures and packages. This, this study was urgently needed to support the development of family centred care policies within the new system of care and welfare arising from the implementation of the WMO (2007). This is of increasing importance in community care where even though finances may not be actually reduced, rising demand and rising costs per activity mean that in real terms the support for carers is less available than before, and once instigated is becoming harder and harder to maintain.

To decide the research design an assessment had to be made as to within which philosophical background the research questions fitted. In research terms a paradigm is

> *"a cluster of believes and dictates that for scientists in a particular discipline influence what should be studied, how research should be done, and how results should be interpreted"* (Bryman, 2012, p630).

For this study, the different philosophical dimensions of epistemology and ontology needed to be carefully considered. While epistemology is seen as the study of, and development of knowledge, ontology, relates to how an individual perceives and feels their reality, thus, questions of social ontology are concerned with the nature of being and meaning of social actions and interactions (Wahyuni, 2012, p69). Epistemology is concerned with what is (or could be) regarded as acceptable and accepted knowledge within a discipline (theory of knowledge) (Bryman, 2012, p27). The most usually discussed epistemological approaches distinguish between positivism and interpretivism. With the former, a fundamental assumption is that there is one reality that can be studied and understood. Reality is seen as objective, existing independently of human observation and creations of the mind. So, for this group, the real world is driven by natural causes and their ensuing effects, and the aim of research is to understand the underlying causes of phenomena, using quantifiable and repeatable measures of assessment. Personal beliefs and biases are excluded to avoid what is described as contamination of the phenomena under study. Thus, the positivist usually uses quantitative methods and procedures with tight controls of the research situation, particularly when seeking to formalise cause and effect through testing hypotheses. The emphasis in both data collection and analysis is quantification (information is measurable), with statistical analysis being key to the study. Most testing is based on deduction, for verification of theory, which in turn guides the research. The research design is fixed and pre-specified, the sample size has to be adequate for generalisation. A positivist seeks generalisations and believes in the power of replication. (Polit & Beck, 2012, p12).

In contrast, interpretivists want to gain insights into the subjective meaning of social actions and interactions, so see major differences between the lived experience and the objective nature of the natural sciences. For these researchers, reality is contextual, time and place specific. The emphasis is on increasing the understanding of human behaviour, not finding one explanation as in positivism (Bryman, 2012, p28). An interpretivist explores and seeks understanding from the people themselves, aiming to uncover insider perspectives and/or what participants see as the real meanings of social phenomena in which they are involved. Thus, the researcher is an integral part of the phenomena being observed, and has to accept that their own subjectivity and values influence the research undertaken. Usually, in this paradigm, qualitative research is used with the researcher using strategies of inquiry that include narratives, interviews, descriptions and observations. Research questions are open-ended and explorative. Sample size for data collection is small. It is about gathering in-depth information to gain deeper understanding of the subject being studied and data should provide rich descriptions of specific social constructs. Data-analysis is inductive as the aim is for the theory to emerge from within research data and not deductive as in positivism where established theory guides research processes.

The emphasis in this study was to gain insights into the carers' perspectives, and understanding of their points of view regarding caring for a loved one with dementia. As the aims dictated that this needed to be an exploratory study, with emphasis on words and their meaning, not on quantification or standardisation, an interpretivist approach seemed most appropriate. Then too, the decision had to be main as to whether in this study, the social actions and interactions can and should be considered as relatively objective, with an external and independent reality for the social actors involved (Bryman 2015) where the social phenomena and their meanings have an existence in which the social actors participate. Or, whether they can and should be considered as social constructs built from the perceptions and actions of the social actors (social constructivism). Reality is seen as multifaceted and subjective, constructed by the individuals who live it. Social phenomena are continually being created and revised, as participants create their own reality (Bryman, 2012, p33). For this study, the latter approach seemed more appropriate as the study has a strong ontological dimension, so from within this paradigm an approach was needed that enabled roles and interactions in different setting to be considered. The carers have been expected to manage and carry out the multi-faceted tasks of caring and they needed to be able to explore all of these with the researcher. An approach supported by recent government changes which include the initiation of the client governor role, designed to support their statement that carers must always be part of the caring process. Therefore, this study needed to include exploration of the extent to which carers were aware of these changes, if so, their perceptions of the social policy changes, the awareness of the roles they are now expected to take, and the impact this has had on their own life, the lives of close family and where appropriate extended family and friends.

In considering which interpretive research strategy would be the best to use, individual approaches such as narrative studies, ethnographic approaches and individual case studies were all rejected as they would not fully address the aim of the study. The two possible phenomenological approaches descriptive phenomenology and hermeneutics ere also rejected. The critical issue for descriptive phenomenologists is to gain insight into the lived experience exploring perceptions, thought, memory, imagination and emotion are all explored. Herneneutics, an approach based on acceptance of this subjectivity. For hermeneutic researchers, the question is to increase understanding of the meaning, and the being, of the phenomenon being studied. For this study, the emphasis was on gaining insight into relatives' perspectives, to ascertain what they as a group wanted and needed from the professionals and organisations, not just what they had already experienced. Therefore whilst Descriptive Phenomenology and Hermeneutics were considered, and could have given useful insights, neither would have fully addressed the questions.

A theoretical perspective was needed that would support the processes of data collection and analysis within the context of the lives of the carers. Initially psychological theories and processes were considered, but the focus was on the ways in which they interact with their loved ones, with family members and with professionals, and the differing roles they needed to take on as they strived to be a partner, parent, sometimes a child or a worker as well as a carer and advocate for the individual with dementia. Therefore the more sociological approaches were considered, and symbolic interactionism offered a philosophical framework which could be used to develop and implement the study. Using symbolic Interactionism, individuals are seen as being self-aware, able to see themselves from the perspective of others and adapt their behaviour and interactions accordingly (Heath and Cowley 2004, p124). Thus, symbolic Interactionism seeks to explore how people and places, times and troubles, actions and accomplishments all interact as individuals try to make sense of, and understand their changing world, consequent actions and the roles they are expected to play in the different settings in which they find themselves. Charmaz (2014; p262) takes this perspective further arguing that people act and interact in response to how they view their situation. This includes reflecting on how their actions and those of other people affect specific situations, and subsequently altering our interpretations of what is, was, or will be. This viewpoint therefore tends to the belief that as individual responses and interactions arise from each other and are reciprocal, then the meanings and changed roles that follow are to some extent consequential" (Creswell, 2012, 423).

What was important for this study was that symbolic interaction describes the family, as a 'living unit of interacting personalities'. In an interaction between at least two persons it is possible to see the development of roles. Roles are based on expectations that evoke behaviour as expected responses. (LaRossa & Reitzes 1993, Carter and Fuller 2015) These roles are all based on the symbolic meanings attached to each role. Therefore how members of the living unit (family) respond to a situation is determined by how they interpret it living with a person with dementia means continually changing roles, expectations and the behaviour of all the members of the unit!

If insight can be gained into the symbols of the family as a living unit, health care professionals can better understand the interactions and behaviours of each member. Through the symbols they know and use, each member is able to communicate with the other members in their living unit and thereby share experiences. (Peterson, 1986, Krueger and Casey 2014) If the accepted communication processes are not used or followed, interactions, experiences, expectations and behaviour cannot progress as expected, which in turn can lead to tension and unhappiness in the unit. Within symbolic interactionism, the method of choice which has emerged for exploring these lived and changing roles and experiences is Grounded Theory. It aims to go beyond describing stories or experiences, arguing that it is possible to use the data to go further to generate or discover a theory for a process or action. Its focus is on exploring with participants, on trying to explain or gain increased insight into and hence understanding of participants' perspectives, seeking for shared or at least reciprocally reflected issues. The argument is, that by using an iterative approach with participants it is possible to work towards achieving consensus. This in turn can be used to move inductively towards developing tentative theories from within the data sets gathered. Thus, findings and potential or suggested theories are said to be 'grounded' (based) within the data collected from participants who have experienced the actions and interactions. From the findings, a framework can be developed to stimulate and support further research (Cresswell and Poth 2017).

It is argued that it has been developed for the purposes of developing small scale, not grand theory from the data and phenomena under study (Strauss & Corbin 1990, 1994, Glaser 1995, 1999, Charmaz 2000, 2014). Thus, in grounded theory, the 'theory comes from within the data'. At no time does the investigator attempt to impose a theory from another study onto the data. (Katz et al 2017). Instead data from participants determines what is explored in the research, the literature searched, the actual questions used and the number of participants in the study

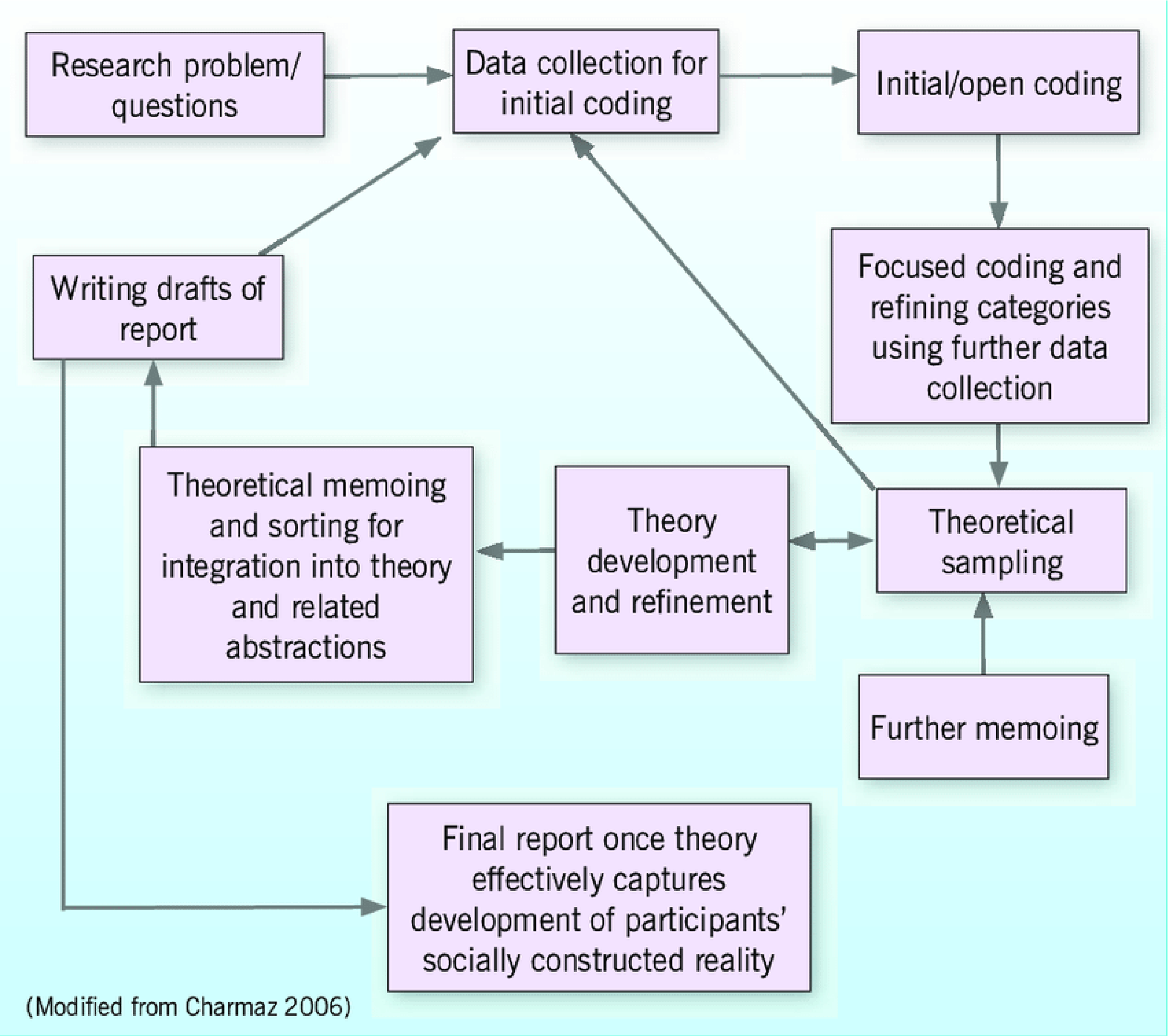


Figure 4.1 Diagram of a study modified from Charmaz

The data from participants sharpens the focus of the research question and related general questions. (Cutcliffe 2000) and it determines the information sought. Coding is the core process in classic grounded theory methodology. It is through coding that the conceptual abstraction of data and its reintegration as theory takes place.

To remain truly open to emergence of theory is among the most challenging issues confronting those to grounded theory. It requires the researcher to enter the research field with questions rather than hypotheses and interview protocols that are flexible and will adapt from interview to interview depending on the data shared by participants. While knowledge of the issue is important, ongoing extensive reviews of literature occur as the study progresses guided by the data gathered. The researcher needs to remain open to exploring phenomena raised as substantive issues, allowing the concerns of those actively engaged therein to guide the emergence of a core issue. An important advantage for this study.

Originally credited to Glaser and Strauss (1967), Grounded Theory research has clear and structured characteristics. The study processes are iterative with simultaneous involvement in data collection and analysis, during these analytic codes and categories are constructed from within the data, not from preconceived logically deduced hypotheses. The iterations, or constant comparisons occur during each stage of the analysis and this helps advance theory development as each cycle continues to build upon previous data analysis. To support the raw data, memo-writing is used to elaborate categories, to specify their properties, and to define relationships between categories, and identify gaps. Sampling is purposive and not random, aimed toward the generation of into and where appropriate theory construction for the specific group of participants and not as with positivist research for population representativeness. However, perhaps one of the biggest differences is that literature is used to support the findings and to enhance insights, not as a base into which the data can be slotted, therefore it is not unusual for to conduct searches at key points in the study, often after conducting an initial, independent analysis (Charmaz, 2014, p7)

In the years following their initial work Glaser and Strauss (1967) separately refined and modified their early research. The Glaserian version of Grounded Theory or Classic Grounded Theory follows the original open and iterative approach (Charmaz, 2014). However, Strauss with Corbin (1990; 1998) developed a more prescriptive form of Grounded Theory (Straussian) with preconceived categories and frameworks which have led to concerns about validity and reliability particularly with regard to theory generation. According to Glaser (1992), these concepts inhibit the possibility for theory to emerge from the data during the process of research, because there is no active conceptualization of patterns or connections in the data while accepting the principles of grounded theory. Charmaz (2006) took an alternative position to both the classic Glaserian and the Straussian Grounded Theory, developing the constructivist version of Grounded Theory. In her opinion, both Glaser and Strauss (1967) and Strauss and Corbin (1990; 1998) were much too systematic in their procedures. She argues that strategies must be more flexible, and that the meanings and perspectives of participants need to be more emphasized. (Creswell, 2012, 424). The difference between the two initial approaches and Constructivist Grounded Theory is the focus on interpretive understandings of participants' meanings, rather than aiming for a conceptual understanding of social behaviour. According to Charmaz (2014), the latter is a more objectivist point of view of Grounded Theory:

> "*An objectivist grounded theorist assumes that data represent objective facts about a knowable world. The data already exist in the world: the researcher finds them and 'discovers' theory from them. This view assumes an external reality and an unbiased observer who records facts about it* (p237)

In the constructivist approach, data and analysis are created through an interactive process whereby the researcher and participant construct a shared reality. Meaning does not emerge from the data *alone*, but rather is created as individuals interact with and interpret these objects. Any resulting theory is a subjective interpretation and depends on the researcher's view; which does not and cannot ignore the interactivity and subjectivity (Charmaz, 2014, 234-240). Where previously Grounded Theory sought to identify and conceptualise the main or core category, the emphasis in Constructivist Grounded Theory is on capturing multiple participant's perspectives. It is about giving voice to the participants. Their voices, views and visions have to be incorporated into descriptions of their lived experiences (Breckenridge et al, 2012, p65). One of the clearest comparisons of the difference is that given by Charmaz (2000, 2002, 2006, 2014) who argues that distinguishing between a social constructionist and an objectivist grounded theory is essential, for understanding divisions and debates in grounded theory and indicates ways to move the method further into social constructionism which advocates includes examining (1) the relativity of the researcher's perspectives, positions, practices, and research situation, (2) the researcher's reflexivity; and (3) depictions of social constructions in the studied world.2 Consistent with the larger social constructionist literature, actions are a central focus arising within socially created situations and social structures. Constructionist grounded theorists attend to what and how questions. They emphasize abstract understanding of empirical phenomena and contend that this understanding must be located in the studied specific circumstances of the research process Charmaz (2008)

In the constructivist approach, data and analysis are created through an interactive process whereby the researcher and participant construct a shared reality. Meaning does not emerge from the data alone, but rather is created as individuals interact with and interpret these objects. The resulting theory is a subjective interpretation and depends on the researcher's view; it does not and cannot ignore this (Charmaz, 2014, 234-240). Where previously Grounded Theory sought to identify and conceptualise the main or core category, the emphasis in Constructivist Grounded Theory is on capturing multiple participants' perspectives. It is about giving voice to the participants. Their voices, views and visions have to be incorporated into descriptions of their lived experiences (Breckenridge et al, 2012, p65). Although the three versions (Glaserian, Straussian, Charmaz) may differ in assumptions, standpoints and conceptual agendas, they all follow the same integrated method using inductive logic to subject the data to rigorous comparative analysis and aiming to develop theoretical analyses and increase knowledge, insights and understanding (Charmaz, 2014, p14).

As previously stated, this study needed to take an interpretivist (epistemological) and constructivist (ontological) point of view in order to address the research questions and gaining insight in the carers' perspectives, needs and wants. Thus, the main focus had to be on letting the carers speak, give them voice, hearing and understanding what their views and visions were regarding care for their loved ones, and their own roles in the process. Caring for a loved one with dementia means that carers have a main role in caring from the moment of diagnose and often even before that as they feel something is wrong but can't give a meaning for the sometimes small changes in behaviour from their loved ones. This feeling of uncertainly does often lead to diagnosis, but this can take time. Carers are involved in caring because their position to the ones they love. An important issue is professionals need to remember is that the nature of the relationship between the patient with dementia and the carer differs from the relationship between the carer and for example the professional caregiver. The carers share besides present and future, also a past with their loved ones with dementia, are emotionally involved with their loved one, and may see small changes and deterioration much more quickly than the extended family or the professional caregiver. There are multiple perspectives, multiple standpoints, multiple views of reality, because carers, patients with dementia and their mutual relationships differ. All together this influences, makes, forms, constructs developing optimal ways of supporting the carer. To study all of these with the carers seemed to match with Charmaz (2006)' point of view of Grounded Theory, and this was therefore adopted for the study.

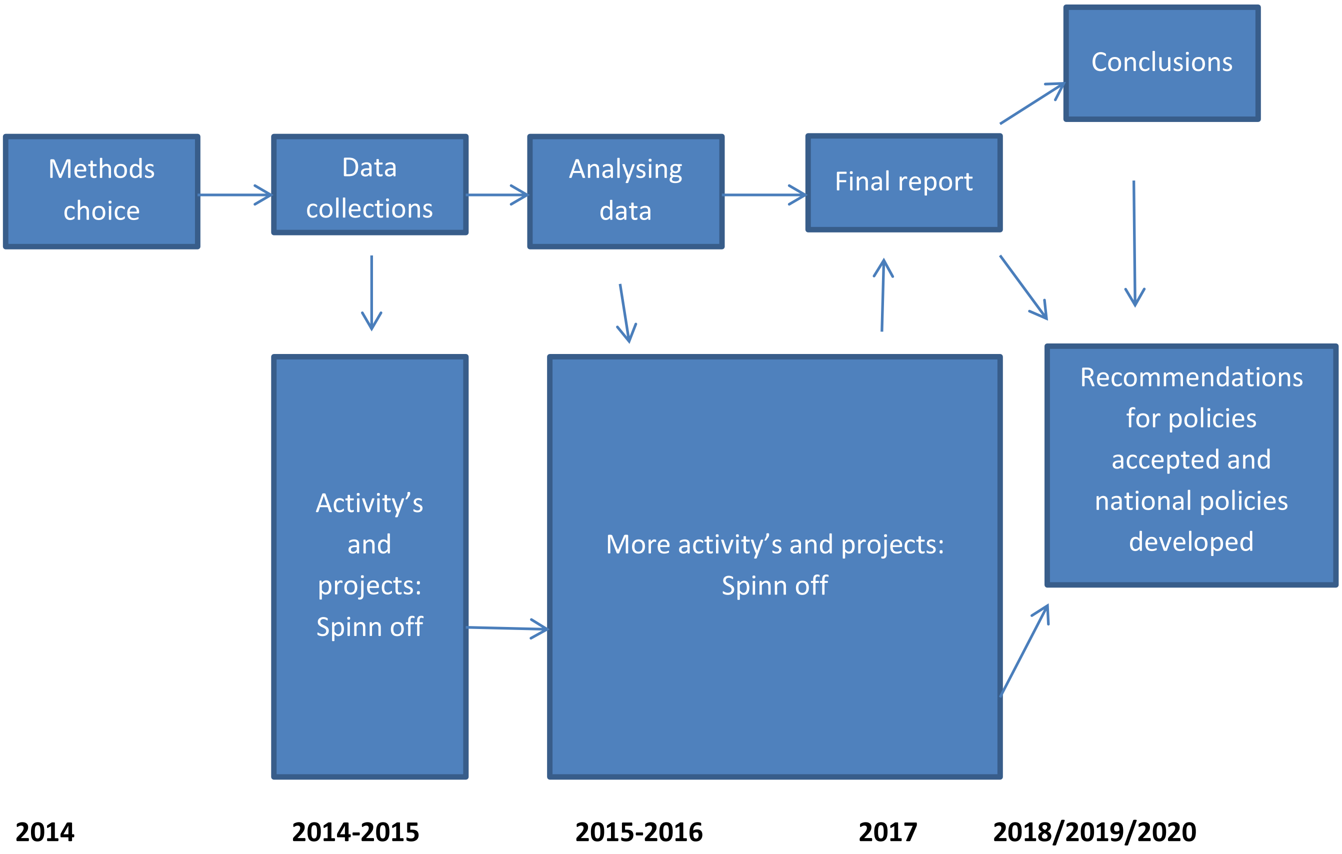


Diagram 4.2: Chronology of the study

4.4: Methods for data collection

Depending on the questions asked, the researcher can use varying forms of qualitative information to collect the data needed, these include interviewing, and participant observation, focus groups, diaries, existing texts and documents, as well as the researchers' own personal reflections. Interviewing is frequently seen as the way to capture best the experiences of participants in their own words (Creswell, 2012, 432-433). The aim is to gather rich, detailed, focused and full data. In the constructivist approach, data have to reveal participants' views, feelings, intentions and actions as well as the contexts and structures of their participants' lives. For the researcher, the first aim is to see their world, from the inside. As Charmaz (2014, p 26-27) states:

> *"Our data collection methods flow from the research question and where we go with it. How you collect data affects which phenomenon you will see, how, where and when you will view them, and what sense you make of them*

This also means that the researcher cannot be neutral or objective towards the subject under study. Both researcher and participant make assumptions about what is real, knowledge, social status and pursue purposes that influences their respective views and actions in the presence of each other. So researchers have to be reflexive throughout, considering and accepting what they bring to the scene, what they see and how they see it. In this study the aim was in-depth information from the research participants (carers) who must be able to speak and discuss their perspective. To do this, a fitting data collecting technique from the constructivist approach is intensive interviewing, where a gently guided interview is conducted to explore thoroughly the individual's substantive experience, giving them voice and thereby enabling the researcher to see the world from their point of view. Characteristics of intensive interviewing are:

- Selection of research participants who have first-hand experience that fits the research topic
- In-depth exploration of participants' experience and situations
- Reliance on open-ended questions
- Objective of obtaining detailed responses
- Emphasis on understanding the research participant's perspective, meanings, and experience
- Practice of following up on unanticipated areas of inquiry, hints, and implicit views and accounts of actions (Charmaz, 2014, p 56)

As, in Constructivist Grounded Theory the product is a more explanatory and discursive narrative, rather than a conclusive theory, the researcher collects qualitative data to try to construct the reality of the phenomenon under study. The process of data collection in Grounded Theory differs from other qualitative approaches, because researchers use a procedure involving the simultaneous and sequential collection and analysis of data. This is inextricably linked with theoretical sampling. Data is collected in the light of emerging categories from earlier stages of data collection and analysis. In the analysis raw data are formed into indicators, indicators to codes and codes to abstract categories. In this process the researcher follows the procedure of constant comparison. This is an inductive process of constantly repeating these steps (Creswell, 2012, 431-434). The emerging findings or theory is constantly checked against reality by sampling data that may challenge or elaborate its developing claims. For this, the researcher applies triangulation, using different data sources or methods, so that findings can be cross-checked (Bryman, 2012, 717). By theoretical sampling the emerging categories and/or theory can be refined until the researcher makes the subjective determination that saturation is reached. This means that new data will not provide any new information or insights for the developing categories. The whole process which leads to saturation is called the emerging design (Creswell, 2012, 433)

In this study I developed an interview guide with open-ended questions (see appendix). This interview guide was based upon the many meetings I had had with carers in my practice. After each interview, a debriefing took place to give the participants the opportunity to ask questions, make comment or add any information that was not discussed during the interview. Also, after each interview it was decided if adjusting the interview guide and the research questions were necessary. The data from the interviews were compared with what is known and had been found in the literature review and previous research findings (appropriateness). The interviews were offered took place in a safe surrounding of the Participant. In every situation they chose their own environment, their own home.

In addition to interviewing, focus groups were also considered as a method of data collection. A focus group is a

> *"form of group interview in which there are several participants (in addition to the moderator/facilitator); there is an emphasis in the questioning on a particular fairly tightly defined topic; and the emphasis is upon interaction within the group and the joint construction of a meaning"* (Bryman, 2012, 712).

Focus groups were included in this research, taking place after the individual interviews. They were used to widen participation to those who were keen to participate, but preferred to be in a group. In this study, as it was considered that any or all participants could feel unsafe alone or in groups, potential participants were all asked if they wanted to participate in a focus group or rather take part, in their own environment with an individual interview. The rationale behind this was that practice had shown me that while some carers are happy to discuss their feelings and problems with other carers, for some there were feelings of grief, shame, pain and quilt, and it was possible that issues would arise that they had not previously discussed. In addition, there could be, and in reality was, concern that potential participants other members of a focus group could measure (judge) each other in the way they care for their loved one, and in their open expression of their feelings. Interestingly two of the potential participants felt they would not participate because they were very disappointed in the support they had experienced in the past period and to revisit that time.

Finally, as early mentioned, in Constructivist Grounded Theory the researcher is considered as being an integral element of the research. I had to be transparent and clear in my assumptions and reflections about the phenomenon under study because they otherwise inevitably affect the emerging design for the conceptual framework. Charmaz (2014, 244) defines this as reflexivity:

"*It is the researcher's scrutiny of the research experience, decisions and interpretations in ways that bring him or her into the process. Reflexivity includes examining how the researcher's interests, positions and assumptions influenced his or her inquiry. A reflexive stance informs how the researcher conducts his or her research, relates to the participants and represents them in written reports".*

Before conducting this study and to maximise the reflexive stance, the researcher composed a SWOT-analysis (Strengths, Weaknesses, Opportunities, Threats), based on self-knowledge, life- experiences and working experience.

STRENGTHS	**WEAKNESSES**
Empathetic Person-cantered communication Asking supplementary questions Experienced Self-reflective Perseverance Responsible Accurate Reliable Inner drive to optimize support for carers in general and for carers from people with dementia in particular Open to receive feedback Well known in this area and subject Flexible	Over enthusiastic Seen as authority Self-doubt Being emotionally engaged, then pitfall loss of objectivity
OPPORTUNITIES	**LIMITATIONS**

Actual developments in supporting carers for and informal caregivers by the Dutch government Focus of stakeholders on informal care Own experience as a carer Motto: whole life learning Life experiences as a person and as nurse Support and cooperation by SIZ Twente for my research Affinity with carers for loved ones with dementia and their relatives	Local governments can see it as prove of incompetence So much attention for the study that consequences are already executed

Figure 4.3: SWOT analysis of the researcher

4.5: Participants

To select the sample, theoretical sampling was used. As mentioned earlier grounded theory researchers use theoretical sampling in the simultaneous and sequential collection and analysis of data. Originally, theoretical sampling was developed and modified by Glaser and Strauss (1967) and Strauss and Corbin (1998) as an approach to qualitative data analysis. Theoretical sampling is a form of purposive sampling, in which the researcher strategically sample cases, contexts or participants, so that those sampled are relevant to the research questions that are being posed. With purposive sampling the researcher samples intentionally with the research goals in mind. Theoretical sampling differs from generic purposive sampling, whereas the former is a sequential sampling process whereby sampling is conducted in order to develop theoretical categories and inferences. Whilst generic purposive sampling is conducted purposively, but not necessarily with regard to the generation of categories and/or theory (Bryman, 2012, 418-422). Charmaz (2014, 345) defines theoretical sampling for ground theory as:

> *"a type of grounded theory sampling in which the researcher aims to develop the properties of his or her developing categories or theory, not to sample randomly selected populations or to sample representative distributions of a particular population. When engaging in theoretical sampling, the researcher seeks people, events, or information to illuminate and define the properties, boundaries and relevance of this category or set of categories".*

In this study the sampling framework was the register of informal carers for loved ones with dementia, registered with SIZ Twente (more than 600) and living in the region Twente (about 600,000 inhabitants, 14 local governments) were included. These could be carers who were caring at the moment or carers who had cared for their loved one in the near past. It included partners, children, relatives and/or friends. The potential participants had to be seen as the central carers: those who have the main responsibility for care, in other words the closest carers.

To minimize the possibility of sample bias, one of the secretaries was given the addresses of the carers and contacted them in the first instance. Contacting was made using randomisation. Carers contacted were asked to participate in this study and their preference for an individual interview in a safe surrounding or their choice, or in a focus group. The search for participants was stopped once 25 participants for an individual interview and in total 100 participants for the 10 planned focus groups were identified. The focus groups were organised in ten different places throughout the region. The formal invitations and consent forms for the individual interviews were send first, once the carer had offered to participate, because in this study the individual interviews took place as the first step before the focus groups. The findings from the individual interviews were used in the focus groups as this is an iterative way of research.

This stratified purposive sampling, where subgroups are identified (the different types of carers) and equally represented (if possible) in the sample size which reflects reality (Bryman, 2012, 419). It supports maximum variation of possible experiences and perspectives among the research participants. However, it was accepted that as there was a delay between the invitation and the focus groups, not all of the selected participants for the focus groups were able to come when the formal invitations were sent. Carers, are busy with caring and many things can affect their ability to find time, for instance a visit to a GP or deterioration in the home situation. Although I knew this, the need to give them a choice had governed the approach used to identify carers willing to join the study.

4.6: Data analysis

In Grounded Theory, coding is the key process, whereby data are broken down into component parts, which are given names (Bryman, 2012, 710). As Charmaz (2014, 342) defines it:

> "*Coding is the process of taking data apart, defining and labelling what these data are about […..]. A grounded theorist creates qualitative codes by defining what he or she sees in the data. Thus, grounded theory codes are emergent. Researchers develop codes as they study and interact with their data. The coding process may take a researcher to unforeseen areas and research questions […..]".*

Coding in Grounded Theory is an important first step in the generation of theory and is initially tentative, which means that coding tends to be in a constant state of potential revision and fluidity. The data are treated as potential indicators of concepts, and the indicators are constantly compared to see which concepts they best fit with (Bryman, 2012, 568). Originally, Glaser and Strauss (1967) described two levels of coding, first into as many categories as possible and then integration of categories (second level). Later on, Strauss and Corbin (1990) developed three levels of coding. They described the first level of coding as open coding whilst Glaser (1978) refers to substantive coding. The difference between the two levels is in the emphasis on emergence. Glaser (1978) starts with multiple data dependent coding and memo-writing where ideas are explored being separated from coding of what is clearly present. These memos are used in the phase of comparison codes and categories, leading to theoretical codes. Finally, in the last level of theoretical coding, categories are refitted and refined which integrate around emerging core. The goal is that theory will be discovered, rather than constructed around a predetermined framework (Heath and Cowley, 2003, 146-147). Strauss and Corbin (1990) distinguish open, axial and selective coding. In the phase of open coding initial categories are formed regarding the phenomenon being studied by segmenting information into indicators and sequentially into codes. An indicator is a small segment of information that come from different people, different sources of the same people over time (Creswell, 2012, 434). The outcomes from this process are concepts, labels given to discrete phenomena. These concepts are later grouped and form categories through constant comparison and revision. A category usually subsumes two or more concepts. The critical issue is to ensure that there is a fit between the indicators and the concepts (Bryman, 2012, 569) The next phase in the Straussian approach is axial coding, in which one open coding category is selected and, positioned at the centre of the process being explored (as the core phenomenon) with the other categories explored for links and relationships to it. These other categories are seen as the causal conditions (factors that influence the core phenomenon), strategies (actions taken in response of the phenomenon), contextual and intervening conditions (specific and general situational factors that influence the strategies) and consequences (outcomes from using the strategies). This phase usually involves a diagrammatic representation, referred to as the coding paradigm, which illustrates the interrelationship of the causal conditions, strategies, contextual and intervening conditions and consequences. In the last phase, selective coding, the researcher aims to identify theoretical concepts from the interrelationship of the categories in the coding paradigm (Creswell, 2012, 425-427).

However, this study follows a constructivist approach, based on Charmaz (2006), with some difference in the overall processes of analysis, distinguishing between two main levels of coding: initial and focused coding. Initial coding is:

> *"The early process of engaging with and defining data. Initial coding forms the link between collecting data and developing an emergent theory to understand and account for these data. Through coding you define what is happening in the data and begin to grapple with what it means"* (Charmaz, 2014, 343).

In the phase of initial coding the researcher has to remain open-minded and work closely with the data, with the aim to explore and generate as many new ideas in the data as possible. Initial codes are provisional, comparative and grounded in the data. Codes need to be short, simple, active and analytic and a way to do this is to code each line in written data, called line-by-line coding. This is coding with 'gerunds':

> "*A heuristic device which brings the researcher into the data, interact with them and study each fragment of them. This type of coding helps to define implicit meanings and actions, gives researchers directions to explore, spurs making comparisons between data and suggests emergent links between processes in the data to pursue and check. It goes deeper into the studied phenomenon and attempts to explicate it".* (Charmaz, 2014, 121).

Line-by-line coding aims for thinking in terms of actions and processes, rather than structures, topics and themes, an approach more usually found in Straussian Grounded Theory. Glaser (1978) emphasised open-ended coding with gerunds, but without having preconceived concepts in mind. Charmaz (2014) argues that as researchers hold prior ideas and skills, this is not possible, they must try to remain open to seeing what they can learn while coding and where it can takes them. At the same time, they must acknowledge their own background and impact on the study taking time to learn and examine how their past is influencing the way they see the world and their data. (Charmaz, 2014, 117). Line-by-line coding works particularly well with detailed data about fundamental empirical problems or processes, whether these data consists of interviews, observations, documents or ethnographies and autobiographies. When coding early in-depth interview data, the researcher must consider what people say and what they struggle to say and what they cannot say. It can identify implicit concerns as well as explicit statements. Engaging in line-by-line coding helps to refocus later interviews (Charmaz, 2014, 125). Other initial coding practices are word-by-word and incident with incident coding. Word-by-word coding is more used in a phenomenology study when working with documents or for example, data from internet blogs. Incident with incident coding is used when conducting a comparative study of incidents (Charmaz, 2014, 128).

After the phase of initial coding, the next step is focused coding. This is:

> "*A sequel to initial coding in which researchers concentrate on the most frequent and/or significant codes among their initial codes and test these codes against large batches of data. Researchers can then take those codes demonstrating analytic strength and raise them to tentative categories to develop. When the researcher's initial codes are concrete, the researcher can code them by asking what analytic story these codes indicate and thus arrive at a set of codes"* (Charmaz, 2014, 343).

Focused coding requires decisions about which initial codes make the most analytic sense to categorise the data incisively and completely. It can also involve coding your initial codes into more conceptual ones (Charmaz, 2014, 138). By developing theoretical sensitivity the researcher can bring an analytic precision in the comparative process of initial and focused coding. They influence each other. Theoretical sensitivity fosters going to the roots of the studied phenomena aiming to specify how it is constituted. It increases the analytical power of the codes and engaging in coding stimulates developing theoretical sensitivity. Engaging in focused coding brings the researcher further in the comparative process and emerging analysis. Throughout this process, the researcher must take a critical as well as measured stance toward the analytical practices being used, bringing their own analytic skills and perspectives and so becoming part of the analysis (Charmaz, 2014, 161).

Generally, when coding, grounded theorists adopt in vivo codes, names or labels that are phrased in the exact words of the participants, rather than in the words of the researcher or in social science or educational terms (Creswell, 2012, 431). The aim is to uncover the meanings of the participants and understand their emergent actions. Useful kinds of in vivo codes are, for example, terms everyone ‘knows’ that flag condensed but significant meanings and participant’s innovative terms that captures meanings or experience. Also insider shorthand terms reflecting a particular group’s perspective or statement that crystallize participants’ actions or concerns have been proven appropriate (Charmaz, 2014, 134). To be able to code, rich data is needed. The data not only forms the materials, but also frames the codes (Charmaz, 2014, 136). When using in-depth interviews as a source for data collection, these have to be recorded and transcribed verbatim prior to coding. Bryman (2012, P482) builds on Heritage’s (1984) arguments that this procedure has several advantages with the main ones being:

- It helps to correct the natural limitations of our memories and of the intuitive glosses that we might place on what people say in interviews
- It allows more thorough examination of what people say
- It permits repeated examinations of the interviewees’ answers
- It opens up the data to public scrutiny by other researchers, who can evaluate the analysis that is carried out by the original researchers of the data (that is, a secondary analysis)
- It therefore helps to counter accusations that an analysis might have been influenced by a researcher’s values or biases

In addition to coding the collected data, memos about the data and coded categories should be recorded throughout the research process. In these, the researcher explores hunches, ideas and thoughts, then reviews them always searching for broader explanations of the work in process. These memos can be observational (describes the situation during the interview), methodological (records of any issues and concerns regarding the methods used) or theoretical (what themes and findings emerged from the interview process) (Wahjuni, 2012, 74). Charmaz (2014) argues that without these, researchers may rely on only what they hear and for a full picture what is seen by the researcher during the interview is also necessary. These notes about these observations of the setting, scene and participant are also data to code. (Charmaz, 2014, 136). (Sim et al 2002 p165) discussed how memo-ing helped her to free associate and write whatever thoughts she became aware of and unblock at times when she felt she could not quit describe in words what was occurring in the data. Also conceptualizing begins, by tracking ideas from raw data to coding and into categories (Creswell, 2012, 439).

In this study all the individual interviews were tape-recorded with the aim of objectivity. All transcripts were compared with the audio-tapes for accuracy of the content of the interviews. Each transcript was repeatedly and thoroughly read to establish familiarity with the data. For data analysis, the processes described above were followed with the line-by-line (initial) and focused coding used in a comparative process, together with memo-writing. The research memos of the participants' reactions to individual questions during and after each interview were also used. With the aim for reflexivity, all findings from each coding process have been recorded in the research journal as a part of interim summaries, and annotated together with the research memos. If appropriate and needed, based on the research memos and reflexivity, codes and/or categories were refined and renamed. Therefore, the process of emerging analysis in the phases of initial and focused coding could be followed by the supervisor. She also peer-reviewed the data-analysis of the transcripts by comparing the coding of the fragments in the emerging analysis with the context in the transcripts.

4.7: Assessing the rigour of the study: trustworthiness and authenticity

For assessing the rigour of quantitative research, reliability and validity are the criteria used. Reliability refers to the consistency of a measure of a concept, validity refers of whether an indicator (or set of indicators) that is devised to gauge a concept really measures that concept (Bryman, 2012, 169-171). Thus, the emphasis is on repeatability and measurement, while in qualitative research this is not the major rationale. Therefore, reliability and validity as defined for quantitative research do not fully apply when assessing the rigour of a qualitative research. Over time, qualitative researchers have worked to adjust reliability and validity to fit with the processes of qualitative research for qualitative research. For example, LeCompte and Goetz (1982) and Kirk and Miller (1986) proposed definitions of external and internal reliability and internal and external validity, as criteria for assessing qualitative research. External reliability is the degree to which a study can be replicated, using specific strategies in qualitative research to approach the requirements of external reliability. Internal reliability means whether there is more than one observer, members of the research team agree about what they see and hear (this matches with inter-observer consistency in quantitative research). Internal validity, assesses whether there is a good match between the researchers' observations and the theoretical ideas they develop, while external validity refers to the degree to which findings can be generalized across social settings. The latter could be a problem for qualitative research because of the problem of trying to generalise from the usually small sample sizes in these studies.

Others, for example Guba and Lincoln (1994) developed a totally different set of criteria for assessing the rigour of a qualitative study. They propose two primary criteria, and these have been in this study: trustworthiness and authenticity. Trustworthiness contains four criteria, namely credibility, transferability, dependability and confirmability (Bryman, 2012).

For trustworthiness, each criteria has key issues for study. A technique to enhance credibility is the use of triangulation, using more than one method of source of data in the study of social phenomena (Bryman 2012, 390). Also checks can be made with participants regarding data given and use of that data. In this study the findings of the interviews were submitted to the participants in a summary to check veracity. This was also done with the reports of the meetings with the expert panel. By doing so, a better understanding and insight of the research issues were facilitated. Also, it provided information if there was a good correlation between the findings and the perspectives and experiences of the participants. Further, contradictory data regarding the research issues were taken into account. The Board of Client Governors acting as an expert panel, added person triangulation. The journal of the researcher was used as a data source, with the aim of achieving reflexivity in this study.

4.7.1: Transferability

In qualitative research entails the intensive study of a small group, or of individuals sharing the same characteristics. The emphasis is more on depth, rather than breadth as in a quantitative study. Therefore, qualitative researchers need to produce rich accounts of the details of the social world under study that is to provide a thick description. Lincoln and Cuba (1985) argue that a thick description allows others to make judgements about the applicability of the findings to other similar studies or settings (Bryman, 2012, 392). By using illustrative examples readers can judge whether emerging concepts and patterns accurately represent the phenomenon under study, referred to as resonance with the reader (Elliot and Timulak, Ch 11,). In this study the participants' and expert panel' quotes were described through a rich and thick narrative. The narrative description of participants' quotes supported the emerged concepts and patterns of the data to resonate with the reader.

4.7.2: Dependability

Lincoln and Guba (1985) recommend that qualitative researchers adopt an ‘auditing’ approach, which means that they should keep complete records of all phases of the research process. Peers should then act as auditors to check how far proper procedures are being and have been followed (Bryman, 2012, 392). Dependability promotes an element replicability or repeatability, such that future researchers can follow a similar research framework (Wahjuni, 2012, 77***).*** In this study detailed records were kept of all phases of the research process (problem formulation, selection of research participants, fieldwork notes, interview transcripts, meeting transcripts, and data analysis decisions, etc.) in the research journal. The supervisor of the researcher at Thebe functioned as the peer reviewer and audited the followed procedures during and at the end of the study in the research journal.

4.7.3: Confirmability

This refers to the extent to which in order to maximise results reflect the understandings and experiences from the research participants, rather than the researcher’s own preferences. Besides the inquiry audit to enhance dependability, researchers should also keep memos about the data and progress of the research. Thus, the research journal provides an audit trail, in which the research process and research outputs can be checked (Wahjuni, 2012, p 77). As mentioned previously, in the phase of data-analysis, memo-writing was used to sustain the process of coding. Also the peer-review of the interviews and the verified reports of the meetings with the expert panel enhances confirmability of the research.

4.7.4: Authenticity

This area has 5 criteria of fairness. These are Ontological authenticity which is does it enlarge personal constructions, Educative authenticity, does it lead to an improved understanding of constructions of others, Catalytic authenticity, does it stimulate others to action and Tactical authenticity which is does it empowers readers to action) (Bryman, 2012). As the terms suggest, authenticity is generally assessed on completion of a study so is discussed in more detail in the reflections and conclusion of the study.

4.8: Ethical issues

Regarding ethical principles in social research, Diener and Crandall (1978) described these as whether there is harm to participants, whether there is lack of informed consent, whether there is an invasion of privacy and whether deception is involved.

Harm to participants: Diener and Crandall (1978) assess harm as having a number of facets: physical harm, harm to participants' development, loss of self-esteem, stress and inducing subjects to perform reprehensible acts (Bryman, 2012, 135). Generally, according to the SRA's Ethical Guidelines, the researcher 'should try to minimize disturbance both to subjects themselves and to subjects' relationships with their environment' (Bryman, 2012, 136). In this study, speaking about dementia and/or problem behaviour by the relatives may cause feelings of stress (emotions like grief, anger, shame, etcetera). It might have been difficult for the participants to cope with these feelings and emotions. In case such distress occurred, arrangements had been made for them to be referred for counselling to the psychologist involved with the unit of the resident. Also when organisation or care problems (such as carer experienced shortcomings) raised in the interviews, the researcher made sure that the relatives were referred to the right person(s).

4.8.1: Informed consent

This is a key principle in social research ethics, 'it implies that prospective research participants should be given as much information as might be needed to make an informed decision about whether or not they wish to participate in a study' (Bryman, 2012, 712). Similarly, the BSA statement says:

> '*as far as possible participation in sociological research should be based on the freely given informed consent of those studied. This implies a responsibility on the sociologist to explain as fully as possible, and in terms meaningful to participants, what the research is about, who is undertaking and financing it, why it is being undertaken and how it is to be promoted'*.

The SRA guidelines also state that participants should not be under the impression that they are required to participate. They must be able to refuse at any stage for whatever reason and to withdraw data just supplied. Information that would be likely to affect a subject's willingness to participate, must be given so participants can judge if their participation will go on. (Bryman, 2012, 138). In this study, the selected relatives were invited by letter, signed by the researcher and her supervisor in Thebe Lucia Breda (see appendix 1). The aim and design of the research was explained in the letter. Also the nature of their involvement, the procedure and how long the interview is going to take. In the letter the term 'problem behaviour' has been replaced by 'changed behaviour'. This is because 'problem behaviour' is a term used by professional caregivers, not known by relatives. Also the term 'changed behaviour' may be less confronting and closer to the experiences of the relatives. Further, the letter explained that the researcher would contact the relative by phone within a week to give more detailed information and answer questions. In this contact the researcher also informed for the nature of the relationship with the resident and explained the need for this information. The approached relatives could accept or refuse participation by signing and sending back the letter. When they joined in, the researcher made an appointment at where they live. At any time during the research they could cancel further participation. Collected data thus far and (voluntary) given reasons to quit are included in the data-analysis if given permission (Intention-to-treat analysis).

Informed consent expert panel: members of the expert panel were formally asked to participate in a written request. Further, they were asked to give formally permission for this research by signing a statement. After that, the request and statement were signed by the researcher and her supervisor. The expert panel received a copy of the signed request and statement (see appendix 2)

4.8.2: Invasion of privacy (confidentiality and anonymity of participants' data)

According to the BSA statement:

> '*The anonymity and privacy of those who participate in the research process should be respected. Personal information concerning research participants should be kept confidential. In some cases it may be necessary to decide whether it is proper or appropriate to record certain kinds of sensitive information'* (Bryman, 2012, 139).

Confidentiality is linked to the issue of harm to participants. Besides maintaining the identities and records of participants as confidential, it also means that participants must not be identifiable when publishing the findings of the research. (Bryman, 2012, 136). In this study participants' names, addresses and letter correspondences were not stored on hard drives but in a locked cabinet. Research data were anonymised. Identifier codes on data files (like copies of transcripts) were used and also kept with the list of participants in the locked cabinet and electronically on the researcher's password-protected computer. The person who transcribed the interviews was informed about the issue of maintaining anonymity and confidentiality to respect the privacy of the participants, but the interviews were anonymised before being handed over. Also no files include participants' names, addresses, personal occupations or other personal information. For the expert panel, because they want to have recognition of their work, they gave formal approval for their identification to be included in the report (see appendix). The care organisation wished to be seen as fully supporting this report, so Thebe Lucia Breda is mentioned by name in the report (see appendix).

Deception: this occurs when researchers represent their work as something other than what it is. As the SRA guidelines puts it:

> *'It remains the duty of social researchers and their collaborators, however, not to pursue methods of inquiry that are likely to infringe human values and sensibilities.*

To do so, whatever the methodological advantages, would be to endanger the reputation of social research and the mutual trust between social researchers and society which is a prerequisite for much research' (Bryman, 2012, 143). In this study, both participants for the in-depth interviews and the expert panel were as much as informed about the study in the informed consent letter (see appendix). In addition as the Board of Client Governors participated as an expert panel, they were informed in the meetings about the findings of the interviews as the research progressed. The supervisor accompanied the researcher and was continually informed by the audit trail.

Chapter 5: Findings, Results and Discussion

5.1: Introduction

This chapter presents the findings from the interviews and focus groups. However, following Charmaz (2014) approach to grounded theory, data collection and analysis are carried out as an integrated, iterative process that begins with the very first data set. . As this process led to changes and adaptation to the questions asked, the choice has been made to present a 'journey' of data collection and analysis, illustrating how this served as a preparation for the development of the framework the choice has been made to follow this format, and give an integrated discussion expressed as a 'journey' of data collection and analysis. Key issues that arose during analysis are presented sequentially, with the discussions arising from the process given as the chapter progresses, together with, where appropriate, supporting literature. However, the impact of the data, and its application in practice are given after this initial analysis, in chapter six.

In total there were 25 individual interviews conducted within the research see table 5.3.1.1.for biographical details. The focus groups considered of 9 groups with a total of 48 people participating. These were mixed groups of older adults, see 5.10.1 for biographical details.

The aim was, for the findings from the individual interviews to give rich detailed data that could be used to inform the focus groups. The initial number of 25, although relatively large, was seen as an appropriate starting point as it would support the maximum variation possible for this qualitative study, from within the wealth of positive responses given during sampling. However, it was accepted that if there were no indicators of saturation after the 25 interviews, it would have been practical and easy to resume the sampling process and continue the interviews with additional participants.

It was also thought that people would be more comfortable and able to share their lived experience in an environment they designated as safe. Therefore participants had been given the choice of where they wished to be interviewed, and without exception, for the individual interviews participants chose their own home. This decision had an added benefit, giving the decision of venue to the participants helped to reduce the possibility of power inequity between researcher and participant (Bravo-Moreno, A. ,2003) in the This strategy proved to be openly appreciated by participants, with the individual interviews providing a wealth of information. The participants chose to raise issues that they saw as important, but that had not been included in the initial set of questions and topics. As a result, this strategy was followed for the focus groups, where participants were given choices of two to three possible venues, and places selected that the group members approved of. Again, participants willingly discussed all the issues and outcomes of the individual interviews, but it was interesting to note that none of them actually initiated discussion on the more sensitive and emotive aspects, but once raised they readily joined in discussions and shred their lived experience. This illustrates some of the differences between individual and focus group interviews (Bryman 2012), and it is important to recognise that had the focus groups been held first it is possible that some of the issues freely discussed in the groups might not have been raised. Nevertheless, the sharing of these issues enabled additional rich and detailed information to be gathered, with some, from this second group of participants openly stating that they had benefited from the support offered by the group, and that it was *' a relief not to be the only one….'.* They had found it reassuring to hear at first hand from others struggling with the same issues, and this in turn led to an unplanned benefit in that in a some instances participants decided to stay in contact and support each other. I was only informed of this some time afterwards, but the typical explanation was that this '*was just what I needed'* and '*I felt... an empathy… they really understood'* the were so pleased that the focus group had enabled them to meet, share with, and, where they chose, to establish links with others with similar problems.

5.2: Step by step

As the study was based on grounded theory, it was accepted that although the first step had been to identify key issues and design a limited number of open questions to start the individual interviews, these first questions would probably need to be adapted and changed as the interviews progressed. The aim was to have a guide for the discussion, but care had to be taken that these questions were not leading, and that they left the interviewee feeling free to discuss and describe their experiences without having to follow a formalised set of questions. There had to be a good balance between the questions and everything the interviewee wanted to say about their own experiences. The initial set of questions was developed based on my experience of more than 35 years of experience working with this group of people and relevant supporting literature (see appendix 1). The iterative processes of analysis began after the first interview, and this included an initial review of the researcher chosen key topics and questions, to check that what I had seen as key issues, reflected the perspectives of the interviewees. Any change in the apparent importance of an issue, based on the lived experience, together with new areas raised by interviewees was then used to guide and underpin subsequent interviews. Formal coding and tabulation took place after every five interviews.

5.3: Next: the interviews

Potential participants had been identified from within the data base of the total population of carers know by Stichting Informele Zorg Twente. (SizTwente) Randomisation within this data base was used to identify those to be approached and asked if they wanted to participate in the study. They were all given time to consider whether or not they were willing to join in. Only after a period of reflection was their answer accepted and if positive, they were given the choice between an individual interview and participation in a focus group. The selection process was halted when the initial 25 interview participants had been found, and over 50 participants had volunteered for the focus groups. However, had more participants been needed, for example if the initial sample had shown no evidence of saturation, as stated above, the randomisation process could have been resumed? It was accepted that this was a large sample of in total 73 potential participants, but with dementia, where it is known that there are many different diseases that can lead to dementia and the disease trajectory varies, maximum variation of participants was seen as very important.

It was in fact remarkably easy to find the people for the interviews. Those contacted all knew both the organisation Stichting Informele Zorg Twente and myself, and within one month all the potential, participating carers had been identified. They were enthusiastic about the study and stated that they welcomed the opportunity to talk about their own situation. Inevitably some declined the invitation, but it is important to note that potential participants in this group mostly wrote to explain their reasons. From those that declined the invitation, the main reason given for not participating was that the burden of care was too heavy and the subject was just could not find the time to participate. In addition, sadly for two, who chose not to participate, they articulated in their response that they were so disappointed by the reality of the caring experience that still did not yet feel able to openly discuss their feelings within the study. These two individuals gave reasons that exemplified the need for the study, and at the same time raised an ethical issue for the researcher. The decision not to participate needed to be respected, but these individuals could not be left in this parlous situation if they and their loved one were to have the best possible quality of life, so outside the study, care and support were mobilised for each one of them. As a result they both gave permission for this anonymised statement to be included in the study, because had they not been invited to participate they would still have in their words been '*standing alone'*.

5.3.1 The individual Interviews.

5.3.1.1: Biographical information from interview participants

	Individual interviews
Number of participants interviewed	25
Male	5
Female	20
Care for:	
Partner	16
Parent	8
Family (aunt)	1
Living in same house	16
Age of carer on average	67,2
Care for how long on average	(7.96) 8 years
Living in a city	20
Living outside a city	5
How many hours of care per week living in the same house	24 hrs a day !
How many hours of care per week on average when living separately	11.75 hrs
Distance in travel time from loved one average for those not in same house	16.8 minutes
Physical Health of carer	Good 68% Average 25% Bad 7%
Mental Health of carer	Good 37% Average 63 % Bad 0%

Table 5.1 Biographical information from interview participants

5.4: Next: The first interviews

Although as described previously, full coding took place after the first five interviews, the initial analysis had a major impact on the steps that followed. Therefore, it was decided that the initial analysis from the first two interviews, would be presented as these two give the first indicators of shared issues, experiences or concerns, and initiated the modifying of future interviews (Charmaz 2014).

The analysis started by reading through the transcripts line by line, checking each comment and marking the separate experiences, ideas and feelings mentioned about caring for a loved one with dementia. The whole data set was read repeatedly, to give full consideration to any emerging patterns from within the data. The identified comments were then given initial groupings and used as examples of the participant's experiences and feelings. This approach enabled the researcher to look for specific words or contexts within the text in order to gather insight into the lived experience. At this stage, it could not give the researcher an in-depth meaning of the text, instead it used the words and/or context to explore the perceptions and descriptions of the participants. With this approach, specific responses could be grouped together and the data then reviewed in the light of the identified key words and phrases. This process provided the basis for the initial formation of categories which would then start the process of data reduction from which the final themes would then formed. For clarification, the four distinct groupings which emerged, were each colour coded.

5.4.1: Initial coding and grouping of identified comments

Initial coding	Text example
Motivation to care	**Positive** **…. I want to care as long as possible…** **…. It makes me happy** **…..I feel sorry for my loved one** **Negative** **…. I should do more and …. feel guilty** **….. It feels like a heavy burden** **….. I feel constant pressure …. have to be there 24 hours a day …7 days a week**
Need for Support	**Positive** **…. I get help from my family and friends** **… The professionals …..offer me support** **… I get the support from relatives** **Negative** **… I get no mental support at all** **….I need more help…. But …can't afford it** **Technology** **…I cannot imagine how technology can support me**
Wishes	**Needed** **…. Better contact with the professionals** **Personal** **….. Be honest to yourself and …your surrounding … Be prepared and look for information**
Impact of the interview Self-value and Recognition of the individual journey	**Impact on the interviewee** **…….Now I know that I am not the only one** **….. it feels so good to talk about my experience**

Table 5.2: Initial coding and grouping

From the initial analysis process for these two interviews it was immediately evident that the carers wanted and needed to talk, not only about their reasons and motivation for being carers, but about their experiences. They wanted to share what it meant to find themselves in the position of a carer, to describe the impact this had had on them as individuals and on their relationship with the person they were caring for. It was evident that, as given in the table above, both participants had some shared experiences, with some issues so important to them, that they needed to be fully explored, in future interviews. Their two main concerns were, firstly, the descriptions of major changes on the life and lifestyle or the carer, and secondly, and their feelings about what had happened to them and their loved one, as the example below illustrates:

> *'The heaviest …..thing [*about caring] *is … that I lost my freedom ….completely…* [I] *was not prepared for that ...I had to be there for him …24 hours a day … 7 days a week… I was desperate when that happened …I couldn't even go shopping without having someone watch my husband…Its so very heavy caring…* [for him]*'*

Both interviewees reported feelings of extreme distress as they tried to struggle on but *'couldn't seem to find help'*. They had each retrospectively recognised that their problems had begun well before diagnosis, and that during the initial stages of their loved one's dementia they had been trying to cope in the absence of a diagnosis and in consequence, without any professional support. The challenges they had faced had had a major, adverse impact on both couple's relationships, with the problems that arose with pre-diagnosis interactions and communications, having led to actions that still impacted on them. One described these long term effects as '*devastating'*, and for her, looking back over time her treatment of her husband during the phase between symptom manifestation and diagnosis had left her with an additional burden of guilt that '*haunted her'.*

> *"At first I didn't realise my husband had dementia ... I was only mad at him because he did things that he never did [*before]*… I thought he was teasing me …and I did not understand why … I was soo... Mad that I* [felt I] *could even hurt him and kick him … And now I feel so guilty about that…'*

Try as she would, she could not forget the things she had said, or the way she had treated him, and for her the tragedy was that by the time she realised what had happened, her husband was no longer had the cognitive ability to understand what she was saying. She had never been able to tell him of her contrition, she could not explain to him why she had reacted as she had, and as a result she carried with her what she described as the unforgettable burden arising from not ever being able to gain his forgiveness.

These findings were so strongly and repeatedly expressed, that it was decided that that they needed to be included in future data collection. As the interviews progressed, openly asking about the **personal impact** of caring, not just **their experience** of caring became one of the strongest focal points for discussion. It was as if it opened a door, once raised, it seemed to give participants permission to say all the things they had kept locked inside themselves, they were able to give voice to their deepest feelings and to share their distress at their negative reactions both pre and post diagnosis. For some there was an open acknowledgement of the '*relief at being able to say at last'*, for them, this was the first time that they had been able to *'unburden'* themselves and recognise that the whole lived experience had been like a roller-coaster which didn't end, but '*went on … and on….and on'*, as they carried on their own personal journey with their loved one.

Reflection

The personal impact that the interviews had had on the interviewees, was unexpected, as was the way that their comments affected me. I was made profoundly aware of the responsibility of projects such as this could have on the participants themselves. I had unthinkingly raised their expectations with the personal interactions, and the opportunity to share with a professional all the things they struggle with. This brought with it, an additional responsibility, I needed to accept that should nothing follow their input, they would feel doubly let down. They had trusted me with their deepest feelings, and their needs could not be ignored, even though in the strictest sense their participation was to supply evidence of the lived experience, ethically their information had to be responded to. Having vocalised their issues and concerns, illustrating what a deep impact being a carer had had on them, they needed a positive response. They needed to know their views and feelings had been carefully listened to, accepted and were valued. Without this, the danger was that they would regret sharing the extent of their concerns and that they would find it harder to trust and share in the future. The deep meaning for the carers was so strong, that it not only affected the design of future interviews, by putting more emphasis on the experience of caring for a loved one. It also had major consequences for me as a nurse, manager and researcher.

It was at this point that I realized that I had to deal with the different roles that I had. And it was at this point that I realized that looking for a direct solution or support from the carer could mean that there could be a delay in the research as a whole. A direct solution that I just had to create as a nurse and a solution for others that I would have to bring about as a manager.

For the nurse, this impact on the carers meant an immediate decision that interviewees must have support, and the reflection that meant I had to look again at my contact with these families. Had I focused on enabling them to unburden themselves, if not I needed to reflect on my own practice. .

For the Manager, the implications across the caseloads of all those with contact with families with dementia needed to be reviewed. Checks needed to be made that all staff were giving time to each informal carer they visited. Without this, how would they continue to cope?

For me as a researcher this meant that I was almost overwhelmed by the openness the interviewees showed. Prior to the study, I had thought that as a mental health nurse had the skills to enable them to talk freely to me. However, these first interviews made me realise the difference between visiting a client/ informal carer, for a planned therapeutic intervention and going with open questions just to listen. I had known that they struggled, but I think that when I looked at these interviews, I felt almost overwhelmed by the personal impact that caring for one loved one meant for them individually. Their trust and willingness to share such personal information, without reservation was humbling to say the least, and confirmed for me that, the importance of specialist nursing research being carried out by specialist nurses. This study seemed at this point to me, to be long overdue.

5.5: The cycle of analysis interviews 3-5 and the initiation of chain of events 1

The issues raised were duly included in the next three interviews, and then the steps of analysis described in chapter 3 were carried out again, but this time including the findings from all five interviews, not just interviews 3-5. The first two interviews, with the initial codes and groupings re-considered in the light of the additional data Table 4.5.1 below gives a summary of the revised initial coding using key extracts from the interviews

Initial coding	Text example
Personal factors in care	
Motivation	**…. I want to care as long as possible…** **…. It makes me happy** **…..I feel sorry for my loved one**
Personal impact	**…. I should do more and …. feel guilty** **….. It feels like a heavy burden** **….. I feel constant pressure …. have to be there 24 hours a day …7 days a week**

Support	
Support needed - practical	**…. I get help from my family and friends** **….I need more help…. But …can't afford it** **… The professionals …..offer me support**
Support needed -mental health	**……I get the support from relatives** **…….I get no mental support at all**
Support needed – technical	**…I cannot imagine how technology can support me**
Wishes	
For my self	**Better contact with the professionals**
For others	**….. Be honest to yourself and …your surrounding …**
Impact of the interview	
Self-value	**...I feel better now I realise what in have done**
recognition	**…. No one seemed to have attention for what I did**
All ages	**…. I was very much confronted as a thirteen year old with the impact that the care had on my mom**

Table 5.3: First findings

As the above table indicates, the iterative analysis process indicated that the initial codes and grouping were still apposite, and therefore, it was possible to place the new data into the main issues of personal factors, support and wishes. While these were still key to most of the discussions, there were one or two additional individualised concerns noted. These were listed separately as it was seen as important to ascertain whether they applied to the wider group still to be interviewed, or just to these last three interviewees, so they too were included in the next set of interviews.

It was now clear looking back at all five interviews that the personal impact or caring was very important for all those who had participated. They had all reported the *'relief' and* being able to talk, and of *'being believed…* 'That they reported that either, '*I wasn't believed... 'Or 'no-one listened.. .'* Is a sad indictment of their perceptions of the 'caring services' they had received? They appeared to welcome the fact that they felt safe enough to say whatever they wanted, and that as one said '*Oh… I've never said anything before'* illustrates the need they had to talk and explain their issues and problems in a safe environment. It seemed as if by giving them the opportunity to explain in their own words, how they saw their lived experience, and focusing on them not their loved one with dementia, created an open door, though which all their concerns, fears, and anxieties could flow. It revealed very clearly the dichotomy in which they lived, they focused on their role as carer, and caring partner, burying their role as an individual in their own right, who had in addition to the feelings raised by the problems their loved one faced, was grieving, without support for all they had lost. This included plans for a shared future, and even as the disease trajectory spread, the loss of the personality and individuality in the one they care for, with comments such as *'he … just isn't the same…,* and '*I do miss my wife… we talk but it's different'* illustrating their sense of loss and recognition of the inevitability of the downward spiral they were witnessing.

Regarding the support these first interviewees wanted, it was striking that none of them could speak with ant clarity of what exactly they wanted:

> *' I need help…*

Or what the much wanted support should entail. The carers could name from whom they received support and from whom they had missed support, but not what support they really wanted or needed. Generic terms are difficult for professionals to interpret and it took time in the interviews to probe and explore in a manner that enabled them to explore for themselves what they were trying to say. It was evident that these informal caregivers did not really accept that they as carers also need personal support and can ask for help for themselves. It seemed that as carers they had been so busy for so long, arranging their lives to fit around the care needs of their loved one, that they were hardly aware of the consequences of lack of support themselves. It was difficult for them to answer question around what they as a carer, needed, and what would help them continue in their chosen role. For me personally, that was the starting point for improving access to the support they needed. It was essential that steps were taken to increase their awareness of their own needs, and empowered to look for and access the range of support available and visible. Professionals must therefore work using strategies to reach out to informal carers and encourage them to come forward, not seeing it *'failing to keep the promise… I made him'* but recognising that only with support could they *'keep going … as long as possible'* this concept was only formally acknowledged by the Dutch government January of this year, in their briefing aimed at improving support for informal carers (Ministry of Health, Welfare and Sport, 2020), but in the absence of additional resources, for healthcare professionals to find difficult to it likely to be some time before the impact of their briefing reaches the carers in need.

It also began to emerge from the data, that some carers see it as their responsibility to contribute to improving the position of carers in a general sense, so that *'others going through the same…'* can be helped. They were therefore eager to share their wishes for themselves and discuss how these could be used to support others. At this point, on reflecting on the interviews and the interview process, unexpectedly it became apparent that there was an important but unplanned benefit for those being interviewed. The interviews had been designed with a short feedback session which allowed the individual to reflect with researcher on their participation. This included checking three important factors. Firstly, that the interviewees had not become not distressed during or by the interview, secondly, that were comfortable with what they had said, and finally, that they were willing for their information to be included in the study. During this concluding phase of the interview, each of these first five participants volunteered the information that whole process of being invited to participate and then being listened made them feel '*special'* and that for a healthcare professional to want to sit and listen to them was '*new… but very important'.* They reported that it for the first time they felt they had been given recognition of their role, with the importance to what they did accepted. All the Interviewees stated they felt '*better for having been able to talk'* a therapeutic outcome in itself.

It was therefore decided that for all remaining interviews the participants would also be asked about the personal effect of the interview process during the feedback phase. This would also help participants to reflect on how they saw themselves as a carer, and allied to that, whether they had ever been asked what the impact of caring on themselves was. The powerful description by one, that it was a *' permanent silent burden'* they carried made it clear that this study, with its ability the break this silence was even more important than initially thought when planning began. These few interviews revealed had the carers '*don't like to complain'* about their situation or to openly state how heavy a burden it had become because they saw such comments as a '*betrayal'* of their loved ones. They were honest, that they trusted the researcher, and valued that they had been *'allowed'* to speak about and share things they found difficult to accept, let alone share. Interestingly, as a researcher, I thought I had invited them to discuss their concerns, but for them it was seen differently. As one said they felt '*safe to talk*' and they saw their interview as being given permission to speak, something they described as '*a great relief',* and illustrates the advantage of a researcher who is known to have an appropriate, trusted professional background.

Reflection

For me as a researcher, so much information emerged from these first five interviews that at first it seemed almost impossible to collate and analyse such a wealth of data, never mind what was likely to come from future interviews. I was concerned that it would all take too long with the interviewees waiting for any help and support to reach them. I could not see how to proceed, but the processes described by Charmaz (2014) approach served as a guide helping me to focus and continue with the research. Nevertheless, it all took much longer than anticipated which in itself proved to be a major learning curve. Prior to this study, in my naivety I had assumed that although research texts indicated how time consuming qualitative analysis was, as I knew the subject area, I would be much quicker. Reading and re-reading the transcripts repeatedly brought new issues and concerns to be tabulated and checked with the data set as a whole, before consistent initial codes and groupings began to emerge.

The nurse wanted solutions . … even if the support was limited to those interviewed. (micro level) and would then try to include this in all therapeutic visits

The manager acts on a meso level and wants to find ways to enable more informal carers to access support mechanisms. So decided to compile local, provincial and national resources.

The researcher wanted to work on the analysis and complete the grouping of data to clarify what needed to be done. The researcher has to deal with the nurse and the manager and …… so decides to seek out strategies carry on the research, and look for ways to work at a macro level.

5.6: The next step: interviews 5-10 and the initiation of chain of events 2

Four of the next five interviews followed the revised pattern, but while interview 10 followed the same structure, it led to an unexpected interaction that had a major impact on the rest of the project and initiated the first of the major steps that led to changes in national policy and practice. It revealed that partners and main carers were not the only group needing to talk and be supported, children and in the instance on this study, a grandchild also struggled with what was happening to their loved relative.

The interview was with a woman in her mid-fifties, caring for her mother who had been diagnosed with dementia. On arrival in their home, there was a teenager, sitting in the same room. She did not take part in the interview, but asked if she could stay in the room and continue with her homework. Her mother was happy for her to stay in the room, while the interview was carried out, openly saying she was happy for her daughter to hear what was said. I accepted their decision, carried out the interview, and on completion of the interview which lasted about 90 minutes, as usual, I gave the participant my business card with my phone number. I informed her that she could call me any time if she had a problem or needed extra information, or even, if as a result of the interview she wanted to be referred to someone to talk about what had been discussed (see method chapter).

However, after I returned to my office, I received an email from her daughter, which was shocking, distressing, and could not be ignored. In consequence, I sought her permission to include this in the study, whereupon, she not only gave permission but stated she would like it to be included, so with her with her approval and support I have included the whole content, anonymised, but otherwise just as she sent it

> *'This morning, you had an interview with my mother. You asked at the end of the interview whether we still had ideas or thoughts we wanted to share. I have been sitting here just by myself thinking about this and looking back. When it became clear that my grandmother had Alzheimer's, my little brother and I were told nothing. I was, at that time about 11 years old and no one, not even my parents, has ever told me what is wrong with Grandma. What it meant then, now or what it will mean for the future. I had to search the internet for myself, and that was not good for a child of my age. At the time I found the information I got very distressing. Now that I'm older, I understand it more and I get to hear some things about her care and what will happen. But back then, all they told me was that Grandma was not good and she would probably die soon, but that's not an explanation of how and why and it's frightening for a child. I could see that my grandfather was very sad and my mother was too. I, as the oldest child, wanted to help but at 11 years you can't do much. My mother could always talk to me, but she couldn't and didn't tell me everything, but I tried, I listened. Within a year I ended up being called the psychologist of the family... but the result of that is that I am now in counselling and needing treatment (and my family doesn't know this). I don't know how or what to tell them*
>
> *My point is: maybe it would be good if information is provided for children. As children we are often underestimated/or not counted, because it is thought that we are not part of the caring ... but I think it is necessary and it would be good if those involved in what is happening* [professionals and families] *took time to take heed of and pay attention to the (small) children, who are suffering too.*
>
> *I just hope this is of use to you and will contribute to your research and wish you every success with your work!*
>
> *Best regards…*

This email illustrates clearly the ethical dilemmas that can arise in research of this nature, to accept this response only in research data terms negates the professional responsibilities of registered health professionals. While the response for future interviews was relatively straight forward, it meant the position and role of children in families with a member living with dementia needed exploration. To do this, there needed to be an additional issue, in the interview schedule designed to focus on how they are perceived and treated by their family members and other professionals. At the same time, of immediate concern was the teenager herself, she had sent me, a mental health practitioner, an email/ letter reaching out for help, in which she clearly indicated that she was struggling with her current situation. However, I needed to make sure that I did not compromise her current therapy, and nor did I want to make contact in a way that would break her trust and confidence by letting her family know how she felt.

Ethically, the role of the researcher had to become second to the needs of the child. Outside the study, as a registered professional, I had to find a way to help her, so I decided to reply to her email thanking her for making contact and offering to find a way to give her additional support. Although this was outside the remit of the project, my professional code of conduct demanded that I respond appropriately to identify need. She chose to accept help, so was contacted by, and is now supported by a colleague who works with young people. However, she was keen that other young people did not find themselves in her position, and wanted her experiences to be used to raise awareness and bring about change.

Reflection

Reading the email was for me the most shocking finding in the data collection of this phase. I instantly had to reflect, not only on the interviews including the topics identified and the interview schedule, but also on my own practice. For myself, my reflections were stark. Did I ignore children and teenagers, did I always ask what do the children know, and did I seek to involve them in care planning. To my own dismay, I could not answer all my question in the affirmative.

I had designed this whole project on the basis that there needed to be a family diagnosis, but where were the children in the project? Then too, I had not looked at whether these young children, because they loved their relative, sometimes chose to take on the role of a young carer. To my utter dismay I realised that I had fallen into the very errors that my project was designed to address, I had not looked deeply enough at the whole family, I had prioritised the main carer, but for a family diagnosis this was not enough. I needed to reconsider the whole project, and look for a new way forward that included this neglected group, and answered their needs as well as those of the adult carers. To do this, I had to find a way forward for my three disparate roles

The nurse couldn’t do anything but act. The child must be supported immediately. There is no other possibility … even if the support is only for this child (micro level) and the rest of the research has to wait.

The manager acts on a meso level and wants to find ways to support all young carers. So decides there needs to be a new system developed to support young carers, as a search through local, provincial and national resources showed nothing permanent was available. Strategies needed to be developed to identify the needs of young people and young carers, which then be used to develop mechanisms to support them. This will take time but is essential as this level needs including

The researcher (as usual) wants to work on the results of this research and deliver strategies to be implemented after it is finished. The researcher has to deal with the nurse and the manager and yet again has no chance…… so decides the professional role will run in tandem with the project activities and aim at a macro level.

5.7: The new direction

Having sadly accepted the outcomes of my reflections, and instituted strategies to support the teenage girl, in the best way that I could at that time, I was the free to review the whole project design in the light of the newly identified needs of this group, as part of the whole family unit. I realised that to develop a model where there really was a family unit diagnosis, the reflections of the nurse and the manager were correct, as a researcher I had to find a way to include children in the family framework. However, from my previous work with young people, and looking at their roles in the family (Slot et al, 2010) it was evident that while they had to be an integral element in the diagnosis, their needs were very different and in consequence they needed a separate programme designed around the needs of adolescents (Roisman, G. et al, 2004) to support them. This needed to recognise their age, growing maturity, interactions within the family and the various ways in which young people choose to communicate with each other. For children who have taken on the role of carer, their situation and needs are again different, but it seemed to me, from the literature (Meulen, M. van der, 2008) that any programme developed specifically for young people could be adapted to meet the needs of this group too. This changed some aspects of the interview schedule, as there was now the additional focus, on children and young people, to enable the proposed framework and model to be designed with them as central elements of all developments, inextricably wound into any proposed recommendations for policies and practice. This did expanded the study context, but looking at the aims, they did not need changing, instead the young people became an explicit, rather than implicit element of the family unit. The decisions made at this stage of the project, led to initiative, after initiative, these while they appeared to run in parallel with the data collection and analysis, were nevertheless an integral part of the total study. They took on their own momentum, continued throughout the project contributed to the development of the conceptual framework and, are still evolving and expanding. This unexpected, but crucial chain of events has been presented sequentially in chapter 6, where its full trajectory can be demonstrated.

The interviews then continued, and as they did so, it was evident that fewer and fewer new issues arose, and it was decided that by the time 20 interviews had been completed, the iterative coding process was carried out again. This confirmed that no more new items needed to be added to the question list. In sampling terms, saturation had been reached. However, 25 participants had been invited to join the study, were keen to share their experiences, and were eagerly awaiting an interview date. Ethically it seemed inappropriate not to include them, if they already felt left out of support mechanisms, rejection from this study could just compound reported feelings of being disenfranchised. A solution was found, as the first few interviews had not included the issues of children and young carers, the decision was made to carry out the final 5 interviews with the additional focus in children and adolescents. However, during these final interviews no further new issues arose, but further rich and in-depth information was gained regarding the role of young people and the challenges faced by parents trying to support both their loved one and the young people.

5.8: Analysis of all interview transcripts

After the first ten interviews, as the process continued, fewer and fewer new issues were noted in the post interview analysis. The refining of the initial coding led to categories that followed on from the first findings, although the focus on some issues did move, the flexible coding (Charmaz 2014) enabled the initial structure to be maintained while elements of the discussion moved and changed. The outcomes of the processes of analysis were tabulated, reviewed, reconsidered and where appropriate refined again. This allowed the researcher to gain insight into the data and to collate the data into themes and sub groups which could be utilised in the next phase of the study, the group interviews.

Although in terms of the whole study completion of the individual interviews was an interim stage in data collection and analysis, as the focus group interviews were yet to be conducted. For clarity and in preparation for the group interviews it was decided to analyse and present a summary of the final iterative processes used for the interview transcripts. By this stage the repeated reading and refining of the data had resulted in tabulated categories and the emergence of themes. Each one of the key themes has been reviewed and presented separately below.

5.8.1: Personal factors in caring

Review and refinement of the initial coding of data led to the emergence of the final theme, personal factors in care, which at this stage was sub divided into two inter-related areas as illustrated below **in table 5.8.1**

Motivation to care –	**Personal impact**
Positive ... want to care as long as possible ...its the way it should be... ...I love the one I care for ... parents cared for me, now I care for them ...on a scale from 1-10 give myself a 7-8	**Positive** ...I get enough satisfaction from caring ...It makes me happy ... feels good to care ...have kept my promise... so pleased... he's still at home
Negative ...gives me no satisfaction at all ... feel sorry for my loved one... all the time ... feel constant pressure : I have to be there 24 hours a day...7 days a week ... just do it... it needs doing ... roles in our relation are turned around	**Negative – general** ... just don't care enough ...should do more: feel guilty ...... just tired...have to fight constantly with the professional care givers ... have to be there always, no change ...no relief ... to cope....feels such a heavy burden **Negative – adverse impact on self** ... left feeling ignorant .. feel powerless ... know have to look after myself better... but don't ... it feels selfish ... left with massive feelings of guilt ... don't understand at first so always mad at him... so sorry now

Table 5.4: Personal factors in caring

The data sets revealed that the additional issue of personal factors had definitely been welcomed by participants, with all willing and in some cases eager to talk about both their personal motivation and the impact their changed role had had on them as individuals. However, most started discussions around their personal experiences with the more positive aspects of their caring role, often discussing in detail they motivation and linked to that, the sheer determination to carry on *'I will manage… I wanted to do it.. and I still care… so much'*. The explanation for this was simple, for this group caring was inextricably linked to their loved for their partner or relative, as one reported *'of course you take care… when they need you…'*. Others simply said *'I love….him/her'*, and from within the small group caring for parents there was a consistent theme

> *'They took care of me* [when I was a child] *and it is only right… it is my duty to take care of them now that they need me'*

Almost unanimously, at the start of their caring journey, the participants

> *'want to keep caring for xxxx in my home for as long as possible… it's where she belongs… we have lived there since we married … it's all she remembers'*.

However, at what had been a highly emotional and distressing time, all they saw was their loved one in need, they that time, they *'didn't know… I had no idea'* what it entailed, or just how heavy the burden could become, and none had envisaged a time when they would reach the point where they couldn't face carrying on and freely contemplated giving up their role. They remembered the sense of happiness that they had felt when they decided that *'I can do this… we will manage…'* For some, this positive acceptance of their role was still evident, it gave them pleasure to think that they could *'give something so essential…'* to the one they loved, enabling them to stay in their own familiar surroundings.

Sadly, for a few, the motivation was somewhat more negative, they talked about caring '*because I have to… it's my duty'* they felt they had no choice, in contrast to those who had embraced this responsibility, for this group, pity was their main emotion. They made statements such as 'I *just feel sorry for him…'* and *'it's just sad… for him… he's lost so much….'.* among these participants, there was an acceptance that they were not doing enough, either because as one said *' I just don't care enough'* or *'I really don't know what would help… I mean I do what I have to.. but…'* It was hard to ascertain how they saw their future developing, they merely went passively from day to day. They accepted that their loved one benefited from being with them but the negative emotions seemed to hold sway, and for them, their continuing role, was just an *unending treadmill … because there's no one else…'*
that accepted that they were doing something valuable but *' I know it's not good enough…. and I should do more'* and it was hard to help them see a more positive side of life, or recognised that what their loved one could still do needed to be nurtured and guarded.

5.8.2: Support

All though categorised as 'support' refining the data from this second emergent theme, revealed three clear sub-themes, mental health, practical support and technical needs. By the largest sub theme was related to mental health and the carers need for emotional support although presented separately in the table 5.8.2 below, the issues were all too some extent inter-related and therefore the discussion contains overlap across the sub-themes. Each of the emerging sub-themes, appeared to be divided into three categories, firstly positive examples, secondly, the negative responses indicating the lack of support. The third sub-division has been labelled as challenges, with the examples given below illustrating some of the challenges faced by the interviewees as they tried to access services. Whether or not individuals had received professional help and support seemed from the discussions, to be idiosyncratic, dependent on the individual they contacted, and not on the official position they held. It has to be a cause for concern that some were '*frightened'* to raise issues in case they weren't believed. This situation has to change with informal carers feeling free to raise all their anxieties and requests for help. It is not acceptable that their experiences have led to them to a point where they feel they cannot approach the very professionals employed to support them, and instead choose to struggle on unaided. At the other end of the scale were those who they didn't understand issues such as technology, and therefore, they didn't know what help and support it could offer, this can be easily addressed through providing information stating what it can offer and providing approved links to IT expertise,

Mental health	**Practical**	**Technical**
Positive ...from health professionals ...I get the support I need ...from a case manager in dementia I get some .... support from my family ...from contact with other care givers .. that helps ... from my GP	**Positive** ... from my family, relatives ... from informal care SIZ Twente ...from health care professionals	**Positive** ,,,can e mail with others ... ...don't need technical support ... find any information in the internet
Negative ... need mental support ... but have no-one Struggle with fatigue... depression ... no help at all ... no support from relatives I get no help at all from my GP ...he did't believe me	**Negative** ...please ... give me more help ... need practical support... but there isn't any...	**Negative** I'm not enough into technical support: in don't understand it
Challenges Afraid of being disbelieved... Frightened they'll think I can't do it Teenager:... protected by my mom but ...many emotional problems as left out of caring	**Challenges** ... I need more help but ....can't afford it ... don't know where to find it ...or who to ask	**Challenges** ... can't imagine how technics can help me

but affected by consequences of caring ... didn't want to disturb my children ...with my own worries and burden ... they can't handle it and I want to protect them		

Table 5.5: support

As this table also illustrates, in the mental health section there were one or two recurrent main concerns in this theme that needed further exploration. Firstly, the role of the GP, and the care given by GPs to these families, especially important, because in the Netherlands the GP has a crucial role as the first point of contact for families. They are the ones who can make diagnoses, or refer onto a specialist for diagnosis, and as such can offer support and guidance for individuals and family groups. However, this study revealed that for some, the challenge of diagnosing dementia in its early stages had impacted adversely on the carers. The interviewees reported having been aware of unexplained changes in behaviour, attitude and communication in their loved one. However, these had not been easy to describe, and unlike physical illness had not been immediately obvious to those outside the close family unit. In consequence when they went to their GP for support, there were reports of feeling felt let down, that they were '*making a fuss about nothing*', as the following extract illustrates. The problem was seen as their misperception and misunderstanding and not their loved one's:

> *'I never had any support from my GP …at first … when I finally went to him to tell* [him] *how worried I was because the behaviour of my husband ….he told me … it was just me …my own perception …he just send me away and told me that yes… my husband had problems with his sense of hearing.. but that was all…I just knew there was something else wrong… after all… I had been married to him for over 40 years …but I thought that …oh well …he was the professional so he must know …but as we know now…that turned out to be wrong… '*

She went on to say how the GP's response of dismissing her concerns had adversely affected her for a long time and that she still had much less confidence than she had had:

> *... I was send away like a naughty child … feeling guilty for telling something 'bad' about my husband to the GP …..and stupid for telling it at all ….because* [he said] *there was nothing wrong……well it turned out to be the opposite….. just six months after that … my husband was diagnosed with Alzheimer's….and in that time he got much worse ….I've lost all my confidence in my GP … do you know…. he never told me that he made a mistake and was sorry that he had made me feel very bad and guilty ….and since then I have never had any support from him.'*

She had been left with an enduring sense of guilt, at the time for even suggesting that her husband had a problem, and later because she had accepted the GPs opinion and had not fought for a referral to specialist help, it had delayed diagnosis, which in turn impacted on her husband's condition. Her loss of confidence in her GP and his evident lack of ability to admit his error, have inevitably have impacted on her willingness to seek further help and guidance from him. The result of this is that her access to support mechanisms is reduced at a time when the challenges she faces mean that she needs all the support possible.

Having read and re-read this I then checked through all the transcripts, and it was evident that although this was the most outspoken criticism, the lack of support or recognition of problems by GPs seemed to be a common factor for both male and female carers. Again, as with the young girl, I didn't feel this could be ignored, so went to speak to a GP (not the one from the participant as that would have broken the promise of confidentiality given to all participants) to ask for his perception and approach to families with a member with dementia. He was interested in why I had contacted him, and having carefully considered his response, explained that on average a GP in that part of the Netherlands will see maybe 2 new cases of dementia each year. The result is that they may not be familiar with the early signs, and sometimes miss the implications of changes in behaviour, particularly when in some instances they appear to them (GP) that they are minor. I did appreciated the GP finding time to speak to me, but have to note here, that according to the National statistics (Nivel Zorgregistraties eerste lijn 2019) , each practice in that area appears to have had rather more than 2 new cases each year. However, whatever the numbers, GPs who will all have rising elderly populations do need to be aware of diseases and conditions such as dementia that increase with age. In the light of the findings and the interview with the GP clearly, what is needed is a training package for GPs in which there should be a strong focus on listening carefully to reports of behavioural change, and with a clear description of possible signs and symptoms. The professional response, whilst realistic, left me with unanswered questions, I needed to know if the GP explanation and the interviewees description were widespread, therefore exploring the perceptions of the role and responses of GPs was added to the interview schedule for the remaining interviews and the focus group interviews.

The second major concern was a stated need for information, from the point of diagnosis throughout the whole trajectory of care. For the interviewees, not knowing what to expect, what the diagnosis actually meant or what was going to happen had made it extremely difficult to cope:

> *'I had no idea what was happening …I simply did not have enough information …It would have been so much easier to have a book about dementia …or if I could have spoken to someone with the same experiences …I wish all the new carers* [could be given] *enough information about what they're going to go through …it is like a journey … …I know I am going to take a trip … but I don't know where I am going …and so ….I don't know what to take with me… in my suitcase'*

Comments such as this arose repeatedly during discussions of the impact of the diagnosis of dementia, scrutiny of all the transcripts revealed that although other terms had been used, the sense of feeling lost, confused and in some instances abandoned was common. Following this review of the whole data set of the individual interviews I then searched for books and other information written for carers regarding dementia, to see if there were resources that I could refer the participants to. There were some books, but most focused only on dementia itself, and were couched in professional terms, hard to use without professional education and training, and overall they did not give the type of information that the participants had stated they wanted. This gap in available information urgently needs to be addressed within the conceptual framework to be developed if adequate support is to be offered following a family based diagnosis, However, again ethically these carers could not be asked to wait two years, so it was decided that work on a toolkit that would accompany the new framework would begin immediately, not waiting until after all data collection and analysis was completed. The emerging toolkit would be refined once data collection was complete, and additional issues raised in the group interviews would be incorporated into the ongoing developments. The processes involved in developing this toolkit are described in more detail in chapter 6

5.8.3: Wishes

The third emerging theme was around the wishes and wants of the interviewees, and were subdivided into wishes for me (the carer) and wishes for other carers. This emerging sub-theme was different in that it did not divide into positive and negative, this was asking the carers what they had on a wish list, rather than what they actually needed at the time of interview. They were also asked what they thought other carers needed, and this fitted with the earlier mentioned desire expressed by some to support their peers and help them to manage better and for longer.

Overall the interviewees were pleased to be asked what they wished for, they interpreted this as a more personal issue, looking at their own lives and discussing in more general terms what wishes they had for themselves, with most looking back on their own experiences and seeing what would have helped at the time. Interestingly, they were much more enthusiastic when asked what they wanted for other carers. This emerging category sub-divided into three areas which did link with the previous emerging themes, but have been given separately because this was more hypothetical than actual. It focused on what they wished for, as an addition to their current circumstances. However, as the table shows, the first two sub-categories focused on information and the professionals, and were clearly based on what had happened since diagnosis. The third sub-theme revealed the emotional toll of their role, and identified clearly the personal challenge that the informal carer bring. The analysis revealed that when asked about other carers, they directly translated what they had wanted or were missing into the wishes and mostly advice for other carers.

Wishes for me as carer	**Wishes for other carers**
Access to information ...Information is definitely needed! ... I want to know what I can expect	**Access to information** ... that they have to know how to take to care of themselves! ... they need to know what they can expect... as time goes on
Role of professionals ...need better contact with professionals ... there need to better cooperation between different professionals... or how can we know what's what ... Better and direct communication with professionals	**Role of professionals** ... good, direct communication with professionals ... good access to information ... good support to help them cope ... to check that they know how to access information!
Personal ... I want to meet other carers in the same situation ... I need people to talk to ...who know...	**Personal** **...** that they have time for themselves **...** that they can get some time off ... just for themselves ... are very clear own position and how to access help and support ... that they can be honest to themselves... about how they feel... what they want

Table 5.6: wishes

The responses in the interviews made it clear that they saw this part of the interview as important, they were providing information that would link directly into the project aims and support the development of the framework and model. Some openly commented that being asked this had

> *' made me feel that what I have gone through wasn't wasted… you can use it to help others…* [that] *makes me feel good…'*

Their ability to turn what they had experienced at the time as adversely affecting their lives into a positive step to help others gave the carers the feeling that their views had been listened to and accepted and they themselves could offer something positive to others either in the same situation, just starting the care journey, or who will care in the future. One of the most frequently made statements, was the re-iteration of the need for information. They had struggled from the point of diagnosis, and this had made planning difficult as *'not knowing what would happen next… how could I plan'*. However, the discussion here was looking long term, they had been given *'bits'* of information and what they really wished for was *'all of it… I would want to know everything…'* This was an important point to explore, as there is a wealth of guidance for professionals pointing out the risk of overwhelming the carer (Blair 2011) when this was discussed with the interviewees, their responses were clear, there were two groups. The first one wanted information given at agreed times

> *'so I would have known… I was seeing the specialist every few months… and it would have been good to know there would be the next bit of info… waiting for me'*

They accepted that the professionals were *'trying to help'...* but felt that they had not really understood how difficult it was to cope not knowing what was likely to happen. They realised that the disease trajectory varies with the type of dementia and that each patient is different, but their ongoing *'fear'* had in their eyes been worse that the day to day reality. It had impacted on all they did. This group wanted other carers to be able to slowly accrue the knowledge they needed, and to be able to see a way forward. The second group had stronger views, they wanted to know it all from the start, they talked about how they had planned their lives with their loved one and now in the light of the uncertain future, they wanted to have *' the chance to think about it all … to plan'*. Their view of the of the struggle to gain appropriate information and to apply it to their own situation was that as one interview reported,

> *it may have seemed better to them… but I need to plan for our future… can I carry on working … do I need to do less ... I felt I was travelling blind…*

This interviewee, although past retirement age had a part-time job he enjoyed, he needed to know how to move on. He didn't want to have to *'let them down'* at short notice, and wanted to be given '*everything'* in a format that would enable him to access information as and when he wanted. His was supported by others, with the *comment 'Information is needed! I want to know what I can expect'* made repeatedly. Their perception of their experiences where they had only slowly been able to find out how the dementia was likely to progress was scathing. In their eyes, it affected their ability to trust the professionals who they saw as '*keeping what I needed* *to know to themselves… it's my family…I need to know…'* Although this question had been designed to give added data regarding what informal carers wanted, in reality it was a pivotal question providing the opportunity for interviewees to use reflection to give voice to their real feelings. This question was alter in the interviews, and it was a measure of the relationship and trust that had built up between research and interviewee that they so freely gave their opinions. It was very clear that the toolkit being developed needed very careful planning, in terms of content, format and delivery time. Both groups were adamant that information was a key element of coping, where they hadn't been offered it, they had had to seek for it themselves, with comments such as '*I would say to them* [other informal carers] **g*et yourself information!*'** For all of them the rear and uncertainty arising from lack of information had adversely affected their ability to cope and the way in which they viewed their loved one.

Added to this need to understand what would happen as the disease progressed, as a strong belief that they had also needed, and not been given, information and guidance on how to care for themselves in the situation in which they found themselves. The changes in their situation had for most, occurred slowly, and it was only *'when I had been caring for him [husband] for years that I realised I had given up on myself…'* This interviewee, had realised that she no longer took time to *'look my best',* she had always in her terms *'made and effort when I go out'* and to her horror had realised that she now just *'put on what's handy'*. For her realisation of this loss of self-awareness had been a shock and she was keen that others did not follow the same pathway, but were *'warned in advance'* and took time for themselves. The interviewees wanted protected time to be built into all care provision, they didn't necessarily see that they needed a great deal of time but were adamant that it needed to start when caring started, as this example illustrates

> *'… Should have paid attention much … and much better to my own position, my need for support.. I didn't take care of myself … and what happens to xxx* [partner] *if I am Ill … or can't cope'*

They wanted for the future what they hadn't had

> *'I would have liked a much better cooperation with professionals and a much better cooperation between professionals between themselves'*

For most of those interviewed there had been, and still is insufficient cooperation with healthcare professionals, regarding both physical care and mental health support. The services they offer and give does not always match the needs as expressed by the informal carer. The real problem appeared to be that in most instances the carers believed that services had not been tailor-made, following detailed discussion and exploration of the possibilities, but was perceived as *'fitting into'* the care organization rather than into *'our lives'* their wish for others was that the revers would happen with the family seen as *'more important than them…* [The professionals]*'.* Currently they saw themselves as lower down what was perceived as a hierarchical structure and they wanted this changed. For both themselves and other carers they wasted support to be offered. As several pointed out they did not really know what was possible, so how could they ask for it. They wanted to be seen as partners willingly offered help, and not left to the time when they have reached the point of not coping and inconsequence were *'dependent on whatever… they give'* To be left until they were in their own words *'desperate'* before being offered support does not meet government policy or good professional standards of practice (Zorgstandaard dementie 2019) and ways have to be found to resolve this situation and enable support and care services to be more pro-actively offered. It was totally unacceptable for interviewees to repeatedly tell me; *'I* [always] *have to fight with the professionals'.* The data from this wants and wishes section needed to be used in the activities arsing as the project progressed, not just in the final conceptual framework and model.

Reflection

Before moving onto the group interviews, there was so much to reflect on. The richness of the data was a revelation. The iterative processes had led to me identifying key points that I had missed on first analysis, but I needed to do a final check that the descriptions and individual analysis had been data led, and not biased by my own perceptions. Also that the way in which I had coded and grouped the data to develop the emerging themes was appropriate. Some findings, such as the letter from the young girl and the lack of support from GPs had been unexpected, and had had major impacts on the project. Further checks had to be made to make sure that leading questions had not been asked, and that data changes had been recognised and used without prejudice.

Another concern, was that if these crucial practitioners were unable to, or did not offer good support, what on earth could carers expect from other healthcare professionals with less responsibility for their overall care. This needed to be explored further in the focus groups, and strategies developed.to redress the negative attitudes to support for informal carers
The final step was to look at the three roles in the light of the data set, and for me it was evident that challenge of integrating these roles to enable the study to progress.

The nurse was convinced that these persons needed the information tailor made on their situation and wanted to go out and help each time the interviews revealed a carer was struggling and needed help

The manager was still determined to develop a whole new method for bringing the information and support to the carers in an early stage of need. Ideally at the moment the diagnosis was made! The format needed to be easy to follow and also to show which professionals to contact, how to make contact with professionals, and the support available.

As usual the researcher wanted to finish the study first and then work on applying the results afterwards. The researcher lost: the information set was seen as an integral element, which needed developing and then using on a wide provincial or national level. The activities to create the toolkit were agreed, developed and from this many information activities were set up, these are discussed later in the dissertation.

5.9: Summary

Looking back at the whole of the interview data set, and the issues that arose, a number of things stood out. The carers had mainly mentioned positive things when asked what motivated them to take care, they want to continue to care, but looking at the personal impact they chosen role had had on them, the loss of self and the negative effects in terms of life and life style could not be ignored. The longer the carer had been trying to cope without any or much support, the greater the loss of self, and it was difficult to listen to lived experiences where the role of the professional appeared to have compounded the problems rather than resolved them.   Their descriptions of their wishes for others, revealed what they really had hoped for, for themselves, they had realised, late in the day, that they needed to take care of themselves and that not doing so made it harder to take care of their loved one, as their own resources dwindling resources made it more and more difficult to carry on. Support from families varied, but clearly professionals planning what support was needed could not rely on all informal carers being supported by friends and relatives. Perhaps one of the hardest things to accept was that most interviewees had continued without help for considerable periods of time, only asking when they were desperate and that when they did ask, their expectations for support did not often match reality.

It was extremely disappointing to find that the GP, was so often referred to giving no support, and in some instances ignoring or disbelieving what the carer said. Yet in the Netherlands this group have a designated support role for this group of patients and carers, and by dismissing their concerns, the GP left the carers thinking that there was nowhere else to go, and no-one else to ask. For some this contributed to a downward spiral, which left them exhausted and finding their caring role harder and harder to sustain. This had an inevitable impact on the relationship between the carer and loved one with dementia, with in some instances the interviewees reporting permanent damage, and an ongoing sense of guilt.

Perhaps not surprisingly, in view of the age of some carers, and social and work backgrounds, technical support was little understood, little used and therefore hardly mentioned. When asked about this, most carers reported searching the internet and using email with the professionals or other supporters, but few other examples were given. Technical support was for many an unknown entity, although they were interested in the idea, accessing such support had not on the whole been considered. For them support was focused on the professional, but from the discussions it was evident that what they hoped for, was not what they received and in consequence, did not meet their needs. They did not what a *'professional take-over'* they wanted the professionals to listen to them and deliver care that fitted within their agreed and excepted social norms. The need for mutual cooperation between professionals was also repeatedly mentioned, but as hoped and longed for, rather than actual. Overall there were clearly so many issues to consider in depth, it was hard to decide where to start, or which processes to try to change to move the carers forward.

Nevertheless, the analysis was invaluable for the development of the interview schedule for the focus groups. The willingness of individuals to share their lived experiences was unprecedented and provided a wealth of rich, in-depth information that made the focus groups, and later the use of the data to change policy and practice at all levels. The ethical dilemmas that arose with this first set of data collection had led to two sets of activities running alongside the main study. Each contributed to the development of the conceptual framework, but the study began to grow exponentially, despite all efforts to contain it and it was important to try to contain it, and not lose the focus of the original study. Nevertheless the findings were so clear and consistent that it was decided it was appropriate to begin to continue the additional activities, while at the same time starting to explore the iterative analysis and reflection, which would continue to be refined and re-defined as the focus groups progressed. The combined data sets could then guide and inform the design of a conceptual framework.

However, by this time it was also evident that the activities that emerged, varied with age, gender, occupational back ground and extended family. Individual activities for young people, the professionals and the carers were all needed, as everyone worked go together offering the best support that they could, while helping to define how the study activities should move forwards. Definitions needed to be developed, for presenting in a format that all the informal carers could follow. They saw it was a way of life, a journey that they were undertaking with their loved one. The most enduring clearest example of that was, as stated in the introduction

> *‘The care for someone with dementia is like a journey… I know I am going to make a trip but I don’t know where I am going to and for that … I don’t know what to take with me in my suitcase’*

This analogy was a revelation, it led to recognition and acceptance of the informal carer ‘journey’, and as such became the guiding concept for the whole study. It identified that for the framework to be completely recognisable by the informal carers and their families, it had to follow their ‘journey’. Therefore, there would need to be signposts and designated places and times to collect information and support. With this realisation, a clear representation of how the intermediate and final framework should look began to emerge.

5.10: The next step: …. preparing for the group interviews

After the individual interviews, the next major step in this study was prepared: the group interviews. The selected carers who had signed up for a group interview were approached and invited to the meetings. These group interviews were held in locations spread throughout the region from which the carers had registered. Some carers, when asked did not want to be interviewed in group meeting near their own home, but reported being willing to join a group in another area, they were offered the opportunity to participate in the group meetings at a different location

5.10.1: Characteristics of the participants in the group interviews

	Focus groups
Number of meetings	9
Number of participants	48
Male	9
Female	39
Care for: Partner Parent Family (aunt)	 41 7 0
Living in same house	41

Table 5.7 Characteristics of the participants in the group interviews

5.10.2: Organising the focus groups

In order to give the participants the maximum possibility to be participate in the study, the interviews were conducted over the whole of the Twente region. Due to confidentiality I had presumed that the informal carers would not like to vocalise their thoughts during the focus group with people from their own residential area. However, this proved to be a clear instance of the professional having a different perception to the participants, with focus group members wishing to be with those from their own area. They openly stated that they wished to discuss their concerns within their locality in order to develop a network of people with similar issues to their own. The interviews were held in Enschede, Hengelo, Haaksbergen, Hof van Twente, Oldenzaal, Almelo en Borne. Using the tables shown above, the preparations were made for the group interviews

The aim of these groups was to enable the group's members to reflect on and discuss the findings from the individual interviews. The analogy which gave the guiding concept to the study was used as a guiding line through the sessions. It was presented as part of the introduction by every group interview session and used to refer to and discuss the experiences of the participants. What luggage do you need for parts of the trip? Or: what do you as a carer need in every phase of the dementia process to carry on? To help them focus on these, each of the main categories was considered in turn, using key but anonymised quotes.

For the very last item: wishes and advices for other carers, a little suitcase was put in the middle of the table to fill it with wishes and advices written on a piece of paper. During every group interview, this activity was the final activity before closing the session. The participants were asked to first think about their wishes and advices for other carers, write in on a piece of paper and then put it in the suitcase. All the participants told each other what their wishes and advices were before putting it in the suitcase. It turned to be very important for the interviewed to support other carers from their shared experiences which allowed them for the first time they could make an important contribution in the support of other carers.

5.10.3: The next step: executing the group interviews

As planned, the first group interviews were developed through the information collated during the individual interviews. This was brought into a Program Focus Group meetings (see appendix 2). The carers that were interviewed were welcomed by the researcher and be brought into a comfortable, quiet room with refreshments provided The researcher made every effort to provide a relaxed atmosphere to facilitate discussions and enable the participants to share their thoughts. The focus groups started with revisiting of the information previously provided which included an explanation of the aims and outcomes of the study including the intrinsic reason for this group interview. The participants were then invited to discuss their concerns if they wanted to I but there was no pressure for any participant to contribute. The interview schedule was very clear but in order to gain as much information possible there was room for flexibility during the focus group interviews so that each participant could discuss their thoughts and concerns.

The first three focus group meetings were conducted and as with the interviews, an initial analysis was held after each one to look for new issues. This was carried out, again using the iterative process described by Charmaz (2014) and the results collated. A more detailed analysis of the data from these interviews with a more structured coding was carried out after these first three focus groups interviews. Much of the data yielded was similar to that gathered during the individual interviews, but interestingly, one new item emerged, the relationship the informal carers had developed with key professional care givers and the position the carers felt they had been given in what they saw as the hierarchy of care.

Motivation to care	Experience of being a carer
Positive ...I just love my partner... so it's right to care ...I still feel so close to my husband even though we can't now have a conversation ... I still enjoy looking after her ... ... When I see that him having fun, it gives me a good feeling...it , gives me energy to go on	**Positive** ... I am the expert in care in my situation... much more than professional ... have had to learn to stand up for myself to stand up for myself ...I have learned so much about what matters... but it wasn't easy
Negative **...** have to do things he did for himself before... but we married for life ... I will carry on ... I've had to say goodbye to husband even before he's dead... but how could I give home to someone else ... ... My partner isn't the same person anymore... but I couldn't bear a stranger to do what I have to do for him	**Negative** ... I feel in my fight to get the support I need... they [the professionals] think I ask things for myself instead of asking for support to be able to carry on ... it gets heavier ... and heavier as time goes by ... my life has changed.. I feel more and more stressed by the situation ... and never see my friends... just for fun anymore ...I always feel guilty... the feeling never goes

Table 5.8 Found motivations and experiences

In this reiterative analysis of the findings and the analysis it was clear that one of the first issues that needed to be addressed was the position of professional care givers (local government and care organisations). Policy documents indicate that the WMO (2007) was designed to make the caring process much easier for the caregiver, but as this study shows, in most cases the converse appeared to be true, with description after description revealing that it made caring more difficult. Informal carers stated they often felt in opposition to the professionals instead of cooperation and support. It was evident that even though the support of informal carers is formally included in the constitution, it was often difficult for carers to access the real support that they needed. The feeling that they constantly have to fight the local government and professional care givers in order to get the support they need was described as '*depressing', 'difficult'* and '*extremely frustrating'*. There was a feeling that there was no respect for the unpaid role that they had undertaken and that the professionals and state did not care about them or their welfare. They highlighted that fact that a large proportion of their time was spent looking after their family member so it was difficult to find time for the constant 'fight' for support and assistance. This situation is not acceptable, these carers deserve support and respect for the unpaid job they are doing. Their role sustains the family unit, enabling their loved ones to stay with their families for as long as possible. Without this group, those with dementia would be bereft of family life, and cared for by professional carers. In the long run, this would over stretch services already working at full capacity and would radically increase social care costs. At a time when due to service constraints it has been, and is difficult for professionals to give the carer the support and time that they need, this could lead services to become overwhelmed The planned conceptual framework needed to recognise this and seek for strategies through which care could be improved. Currently, the priorities between local government and the informal carers are vastly different, and mechanisms to overcome these differences need to be included in policy and practice.

5.10.4: The next step: three more group interviews

During the next set of focus group interviews as much as possible time as possible was given to the participants to enable them to raise additional issues if they wished to, and to allow them sufficient time for them to express their experiences, perceptions and emotions. The individual interviews had shown on of the most important message that was highlighted by all participants was the lack of information that is shared with informal carers about their ability to access support when needed. Every participant indicated that they had not been informed or had received insufficient information to empower them to access this support. This information was everything from the causes and types of dementia, no clarity on the information related to the diagnostic phase, the possible treatment options for dementia and there was minimal mention about support for them as an informal carer with regards financial concerns as well as health and wellbeing issues that may arise. The table below illustrates how similar the comments were to the individual interviews. So much so that sometimes it was hard to believe that these were different people.

Support needed **Mental health**	**Support needed** **Practical**	**Support needed** **Technics**
Positive .....support from my children and family ... from my GP ... The Alzheimer café ... from other carers ... other people ...just to ask how I am... how I feel ... need for emotional support	**Positive** ...a good case manager ...professional physical help... a nurse to visit ... My neighbours will always give me practical support ... other people to help with him physically	**Positive** Information on the internet ... Seek for information! You can't have enough
Negative ... needed support from my church...but it wasn't offered ... lost most of my 'friends', they can't handle it and don't come anymore ...that's very painful. ... none from GP	**Negative** ...bad experience...too many different carers came... no continuity and it didn't help ... not enough practical support	**Negative** ... too much on the internet ... it's confusing

Table 5.9: Analysis of the findings about support from the first 6 focus group interviews

However, there were one or two different descriptions. In one group, for the first time the church community was mentioned negatively, as an organization from which support was expected but did not come. This carer had always attended church and had assumed

> *'they would understand… that's what church should be about…I thought when I told them … they would say they'd be there for me…they would come round… but they didn't even offer.. I feel so disappointed and let down....'*

For this interviewee, the sense of hurt from what she saw as rejection by what should have been in her eyes, one of her strongest supports had added to her distress. It seemed unbelievable to her that they didn't volunteer to help, but just left her *'to get on with it..'* having always followed church reaching and believed what she was taught, the shock of finding that they could just walk away from her had impacted on ow she saw life as a whole. What she had seen as a strong spiritual guide had been found from her perspective to have feet of clay. She had no explanation for their reaction despite having gone over and over it in her own mind. Part of the hurt was for her husband as she had hoped they would help him visiting and sitting with him. This sense of hurt from rejection was also found in the interviewees who found that

> *'… my friends… I know they found it hard… the couldn't cope… but they just stopped coming round… they don't phone… to do this to me it hurts… it's so painful.. I have so few people to talk to now… how could they…'*

The only difference to the first example, was that this second group member had realised that the friends couldn't cope with the changes they saw, but this didn't lessen the sense of hurt, let down and betrayal. For both of them the loss of care and support from trusted sources had added to the burden of caring, and emphasised how much their lives had moved away from what they saw as normal. However much support and help could be given by professionals and others, to lose support and help from those trusted and part of their close circle was difficult to overcome, the effect meant increasing loneliness and isolation resulting in them becoming 'increasingly *dependent on myself as a carer'* They both received support from other members of the groups they were in, who offered warmth, empathy and understanding, and freely offered to keep in contact. Their own commitments meant that phone contact was likely to be the way most made contact, but this was welcomed and it was an unplanned bonus, but both women had had immediate support from their own peer group, a much more effective way to proceed. However, outside the interview I worked with both and did manage to give the additional support mechanisms.

The focus groups tremendous need for information was also frequently shared and recognized by the participants in these group interviews. The internet was more often cited as a source of information. However the internet was not a well-known source of information for all participants as they told they never used the internet at all. They just did not have the knowledge to use the internet.

The participants that told they used the internet there was another problem. The overwhelming amount of information made it difficult to find the right information for yourself as carer at that time.

Wishes for me as carer	Advises to other carers
Information: a book! Information, information and information	Go to all kinds of information gatherings: you get information and also meet other people in the same situation Be open to the outside world
	A list with actual telephone numbers you need
	Make yourself clear for the outside: shout it out!
	Try to find other people with the same experience and talk to them
That I can keep my self-respect	Always try to keep your self-respect

Table 5.10 : wishes for myself and for other carers

The wishes for yourself as a carer and for other carers mainly show similarities with the individual interviews.

The overwhelming need for information was again frequently mentioned and recognized here. In addition, self-esteem was frequently mentioned. "Make sure you maintain your self-esteem." In the group interviews, a difference in wishes for the other carers lies mainly in the fact that the carers are advised to be very open to the outside world about dementia and caring for your loved one , something the carers themselves had not done enough. "Shout it from the roofs" one interviewee said, and this was agreed with the other attendees needs to be written like the other sections.

5.11: summary of findings

As a healthcare professional, it was upsetting to see the dismissive and neglectful manner with which the informal carers had been treated at the start of their journey when their family member first exhibited the signs and symptoms of with dementia. There seemed to be no recognition that they did not choose this role, that it had happened because they loved their family member. They have accepted that they are unpaid, but they reported that among the professionals there seemed to be little acceptance of just how hard the increasing workload was to sustain. Interestingly, because they were caring for a partner or parent, some participants did not regard themselves as carers, which meant that they had not accessed some of the support mechanisms available and were unknown to the professionals, so making it even harder to cope.

The quotes reveal that as before, the information provided to them is fragmented and varies depending on the region in which the client and carer live. Some fragments of information are provided or can be found online but this is often general information about dementia and nothing about the role of the carer, or the support they need. Despite attempts by professionals, the data revealed that many of the carers often have no idea how the information they find could assist them, as the following quote indicates:

> *'I had no information whatsoever about dementia….no one gave me the information and I didn't search for it myself… now I think I was very ignorant ….because I could have searched [*for information]*. ….by the time I* [found] *what I needed … it was too late'*

Others reported that dementia was an unknown concept, they had never really encountered it, had not understood what the diagnosis meant, and so were lost, struggling to know what to do next

> *'I didn't know what kind of dementia my mother had …to tell you the truth… I didn't even know there were more types of illness that can lead to dementia … so I didn't know what to expect. The right information at the right time would have helped me a lot.'*

The importance of accessing and receiving information was mentioned so often that it became a permanent item on the list of types of support needed. The lack of information regarding what support was available, or equally important, how to access it, was a major obstacle that needed to be urgently addressed. One of the biggest challenges they described was that as a result of the WMO changes the support opportunities and options for informal carers were now different in every town. There is a need for a standard information package for the carers, given to them at the moment of a client's diagnoses. This must include information about regional variations as well as national specifics. This issue continued to be repeatedly raised in the remaining focus groups and then all the information was collated as the basis for the development of the information section of the toolkit. This was developed at the same time as the conceptual framework as then the two activities could feed into one another. It has to be accepted that each carer will make their own choices, but it is hard to see how they can make an informed decision when they don't know what is available.

As the tables and discussion above illustrate, a number of issues were repeatedly reported to be important for the carers. Carers need help and recognition of the position they have as a caregiver, they were disappointed that it seemed to them that there was little appreciation from society for all that they did. They wanted to feel valued, to be respected, and treated in a manner that let them maintain their own self-respect, as they continue to care for a loved one with dementia.

The enormous need for information is an important topic for carers. Information about dementia and the development of the disease as time goes by. But also information about the possibilities of support as a carer. The metaphor given by one interviewee of a

> *'a journey with an unknown destination, and if the destination is unknown, you don't know what to take with you as luggage on your trip'*

Sums up the problems when adequate information is not given, and was fully endorsed by other interviewees The wishes for others was often compared to the emancipation or empowerment of the caregivers. It was evident in the both individual interviews and the focus groups that carers wanted to be treated as equals and key members of care planning, not just left to accept what was sent without question, their views were summed up by the comment that *'You have to stand up for yourself, keep control in your own hands'.* In the discussion they made it plain that many carers did not succeed, but mentioned it as a wish and advice that the carers give to other carers. An important topic in the interviews was also the increasing weight of the care for your oved one as time goes on, the burden becomes heavier and carers need increasing support to keep caring in a manner that does not drain all their resources. One of the saddest concerns was that in many cases, carers reported that they were *'slowly saying goodbye'* to their loved one as they saw their personality and ability to recognise others and join in 'normal' life they were grieving for all they had lost, shared dreams and plans, and even a shared future. Their relationships were changing, in some instances, roles were being completely reversed and as some said

> *'to be honest he is gone… I no longer have a partner, I have the physical presence… but that's all'*

They feel that they no longer have a partner, or even someone they can sit and have a conversation with, and that compounded their loneliness.

The data sets also revealed the importance of including all groups, and key family in the living unit in this caring process. Currently, young children are often forgotten, sometimes because parents are determinedly protecting their children, but these very children openly state that that they are and want to be involved and that they are not part of the care for the loved one, while in practice this is the case. Carers need help formulating their specific needs for support. They are always busy with care for a loved one and have not enough sight into their personal need for support. As an example of support, the carers often mention the possibilities of being able to transfer the daily care temporary to someone else to have time for themselves. *'Being able to recharge the battery',* as one of the interviewees told. There is a great need for different shapes of respite care.

The interviewees often mentioned their shame, especially in the early stages of the dementia process. In retrospect, they feel that there is no reason to be ashamed. They translate this feeling into the desire for other carers to give complete clarity to the people in the immediate vicinity. *'Shout it out'* said one of the interviewed carers, 'it helps'. Some interviewees mentioned that they would like to do something with their own experience to help other carers. Their own experience could thus be used positively to help others.

So far, the following found items can be used in the framework to be developed:
Attention and recognition

Information
Look in the future
loss of your partner
say goodbye to your loved one
Shame
the care is getting heavier as time goes by
attention for young people in the living unit
self-esteem
support tailor made from professionals
help in finding the right support
need for respite care
use of the experience as carer
clarity to the people around you

5.12: the last group interviews

One of the group interviews had to be cancelled because due to caring issues some individuals were unable a number of people could not make it at the agreed time. They were invited to attend one of the remaining three, and as this still kept the numbers realistic these remaining more group interviews were conducted. The role of the church was a new item, discussed in groups. The item of losing friends gave an overwhelming recognition within the group discussions. A number of participants brought in the new item of the value of self-respect that was recognised by other group members.

As no more new items were raised, and the findings were indicating a degree of saturation no additional focus groups were arranged. The items provided by the interviewees increasingly confirmed and repeated the items that emerged from the individual interviews.
In the above tables 5.10.3.1, 5.3.10.2 and 5.10.3.3 the items discussed in the group interviews can be found.

5.12.1: Total Findings

After completing all interviews and reaching saturation, the items found are mapped. This concerns all interview data, both from the individual interviews and from the group interviews. The data gathered from the group interviews was added to the data from the individual interviews.

5.13: Analysing all the findings

All the findings were put in a model in which the number of how many times the item was mentioned from the most often to the lowest number. All the items are divided in the motives, the experiences, the different ways of support and the wishes for the carer self or other carers, as these turned out to be the most important themes for all the carers that had been interviewed. Every item of the collected data could be linked to one of these important themes that arose step by step following the method of the grounded theory.
Carefully looking again to all the data it brought an overview of the most mentioned items.

5.13.1: Times each subject is mentioned by the 73 participants

The final analysis was based on all data sets, the processes used led to findings that gave increased insight into, and awareness of the real, lived through input from carers with experience: they care or cared for a loved one with dementia. As a grounded theory approach was used, after new items elicited were included in subsequent interviews and new themes arose that way.

In total the comments from all participants using the process described in the methods chapter, and at the start of the findings, the initial codes were reviewed and ultimately seven categories emerged which were the themed and used as a basis for the discussion. As the table 5.13.1.

below indicates, these codes were quantified to check that it was not researcher bias that had led to their inclusion.

Motives	**Number**
I like doing it, it gives me satisfaction	55
I want to keep my care for my loved one as long as possible	50
I do it out of love for my loved one	45
It's just that way, you just do it	36
I care because i feel sorry for my loved one	3
Experience	
I give myself on a scale from 0-10 a 7 or more	51
I always have to be there, I have no time for myself	33
I have to 'fight' again and again with the professional caregivers	19
I do too little and I often fall short	19
I find it very difficult for my loved one	15
I feel a permanent pressure	6
The roles in our relationship are reversed	5
I feel powerless	3
I do not get any satisfaction from caring for my loved one	2

Support practical	**Number**
The professional carers give me support	52
The informal care gives me practical support	36
I could need far more professional support, I can't get it or can't afford it	15
My family gives me help	30
My family gives me no help at all	9
I need far more practical support	12
Support emotional	
I get attention from my direct environment: family, friends	48
I get emotional support from a case manager	15
The professional carers give me emotional support	12
I need more emotional support	6
Technical support	
May be I could use it but I don't know how	36
I found some information on the internet	12
I don't need technical support	30

Wishes for myself as carer	**Number**
Better contacts with professional carers and [gemeenten] local council	39
More and better information an in an earlier stage	21
More and better 'respite' possibilities [mogelijkheden] like care share	18
Advises to other carers	
Ask for help! And ask it early	49
Take better care of yourself!	40
Find someone who really listens to you	31
Find information	51
Start earlier finding information	51
Be honest and open to your surrounding	30
Be honest to each other!	16
Be aware of your situation	19
Find someone who was in the same situation and share	23
Stand up for yourself	14

Be and stay yourself	6

Table 5.12.: number of subject is mentioned

5.14: Overview of overall themes and key issues

The detailed analysis revealed that while all concepts in the comments were shared, seven concepts were common throughout as illustrated by the example of responses, labelled and given above. From this analysis, six common themes were identified. Each theme needed to be clearly defined, refined and accompanied by a detailed analysis. It was decided that it would be helpful to develop titles that conveyed an immediate indication of the essence of the theme. Main themes were viewed as essential in determining the understandings of all the participants who are informal carers. Arising from the data sets, each of the participant comments have been colour coded as per previous data sets.

The final themes were named as (1) Informal carers need to be supported to care, (2) Respite care, (3) Information, (4) Recognition and Support, (5) Carer must become a respected partner in patients care and (6) Technical support is hardly used but has potential

5.14.1: Informal carers need to be supported in care

The comments from the participants show the need to allow informal carers the support to be able to care for their loved ones. This can done through many channels such as communities, professional caregivers, voluntary organisations and welfare organisations (Sociaal Cultureel Planbureau 2015, p128).

> ***I would like to keep my husband as long as possible here at home…but I can't do it alone and …I don't know where to start. …there are so many questions coming towards me…… (Motives)***

As this quote illustrates, support is vitally important if the informal carer is to provide the best possible care for their loved ones with dementia. The ministry for health in the Netherlands states that for many people, informal care is the most natural thing in the world; they like to do it (Sociaal Cultureel Planbureau 2015, p79). However, while this may be true, it does mean they want, or can to do it unaided and alone. There is a wealth of research demonstrating that that caring for a family member with Dementia is extremely stressful and requires twenty four hour commitment from the whole family unit(Sociaal en Cultureel Planbureau, 20019 , P146). However, despite this there has been little but rhetoric since the WM was introduced but as this study shows there was little or no obvious support offered or given. Indeed, most reported that the absence of support meant that their lives had shrunk to focus only on their loved one, leaving them permanently pressured

> **[from my Experience]** ***I just have to be there 24 hours a day… the pressure is always there..... (Experience)***

For some, this situation was seen as inevitable, they felt that if they ask for help and support their friends and more remote families will think they are trying to opt out, and this will be regarded unit as a negative mark on the Informal Carer themself. This fear of being criticised or castigated was described as adding to their sense of guilt. They have to repeatedly ask for support, and this made some feel that they were asking too much, again leading to a sense of guilt. Also as there were instances when they were expected to pay, they were made to feel they were in the wrong

> ***I always have to fight with home care to get care … that really helps me as a caretaker .. I should given relief*** **[care]** ***and not charged extra ...***
> ***(Experience)***

They felt that they were expected to manage alone, that there was an assumption that they should just carry on, because '***after all, it is your family member'***. In these instances, they reported that they were additionally burdened by the institutions and organisations they contacted. In the light of this it was a concern to find that although they were just supposed to get on with care and cope with whatever happened, they also reported that they hardly ever participated in decision-making about care, or worked in collaboration with professional care. A finding fits with research by the Dutch government which found that within the Netherlands, a significant proportion of the carers, 36%, have little or no say in what is provided for their loved one (Sociaal en Cultureel Planbureau 2015, p 121).

The roles and actions of healthcare providers and local governments were frequently mentioned during the interviews and focus groups. They were clear that where they (informal carers) do not feel supported by Care organisations, it is harder to continue in their role. Talking with professional caregivers from health and social care showed that they perceive that they are doing a good job; that they really support carers. How does this fit here this is supposed to be about the carers not meeting you have had with professionals The carers openly stated that they felt that they depended on goodwill from professionals, so didn't want to upset them. In consequence they did not always tell the professionals what they really thought about the services they received and the way they were treated. It was not acceptable to be told that they were afraid that **'*it would be my husband who suffered not me*'**, if they complained as they thought negative consequences would impact on the care given. Conversely, professional care providers also find communication and cooperation with carers very difficult not sure this fits here either. These informal carers are vulnerable and they are fighting to protect their loved one, cooperation between professionals and informal caregivers must be coordinated much more closely, with carers feeling valued and listened to. Both the client and the informal carer have to become owners of the care, with the right to lead planning and provision, but for that to happen, it requires a change of thought process from the healthcare professional (Zorg en Welzijn, 2013).

Regardless of the relationships they develop with professionals the real problem was that as they did not know what they were entitled to, they didn't know who to go to or what help or advice they can and may ask for from healthcare professionals. They may not always accept their situation as carer and they get the feeling that professionals must want to take over the complete care of their relative. Sometimes, they leave the care to the professionals but they wish that they could assist in this care. Many people who provide care to a partner, parent or child do not know that they are actually caregivers (De Gelderlander 2017).

> ***The home care took over all my caring activity's while I'd rather have done something myself. But then I'm stuck on it, then I have to do that every week or day, and I really do not want to. .... (Support practical)***

For themselves, carers in particular want more support, information about the possibilities for care, less bureaucracy in arranging care, and better communication with and coordination between care providers (Dementiemonitor Mantelzorg 2016)

> ***I wish I had a lot more information. Then I could have made a better choice.......... (Wishes for myself)***

Looking at the data in total, only 18% of all informal caregivers reported having received information, advice or other help regarding support and care of their relative, and interestingly, only 13% of the people used this information, which fits with national findings (Sociaal Cultureel Planbureau 2015). This meant that in this study as with all informal carers across the Netherlands, four out of five carers do not, or cannot easily find any information that they can use to access the information and advice that is available. In this study, for some, where they did find some information it just did not seem relevant to the situation in which they find themselves, and with limited time available they just '*didn't feel able'* to search further. One of the biggest barriers they reported was that by the time they realised they needed help, they were fully involved in caring, and therefore when information did not seem immediately useful it was discarded, and they just struggled on. Also they could not spare the time to repeatedly search the many possible sites

> ***Caring for your loved one just happens to you. Before you know, you're in the middle and you can't*** **[find time to]** ***get it anymore. I should have taken care of myself much better...... (Experiences)***

The caregiver is confronted with a process of loss and changing tasks and roles as a previously equitable relationship changes more and more into a care relationship. As the disease trajectory progresses, they reported that the type of caring needed led to a world they had previously known nothing about. These informal carers had taken on a task that they had envisaged as following the patterns of caring they were used to. They had not and still did not fully understand the difference between caring for someone with physical limitations and the type of care needed for those with dementia. After all, they had had no mental health training and suddenly they were dealing with situations that took more and more toll on them. As a result, the interviewees in this study made comparisons with friends and family who cared for those with chronic illness or disability and reported feeling more burdened than their friends, a finding supported by Peeters et al (2012) study. The majority of carers in this study were the partners, some were trying to care whilst maintaining their own external work, and others were trying to provide long-term and complex help while being elderly themselves. For both these groups, it has been recognised the burden is as they see no alternatives to share the care of someone who in their own eyes they had made a lifetime promise to (De Boer et al., 2009; CBS / RIVM, 2013)

'I just couldn't stop caring because I made a promise the day we were married'

Caregivers are generally not sufficiently prepared for the role of caregiver, as several reported *'it just creeps up on you',* by the time they were fully aware of what had happened to them a *big part of my own life had gone'*. They had lost contact with friends, with their hobbies and even in some cases their relatives as '*visiting is just so difficult'* They had just accepted that they could no longer have *'a life of my own'* their world had closed I and become just 24 hour care. For the interviewees it was a double edged sword: of course they wanted to continue to care for their loved on, but *'it is so hard….'*. They didn't feel they could complain because

> *'Every time I feel I can't go on… I look at him and it's so much worse for him… so I tell myself to stop moaning and get on with it…'*

Linked to this downward spiral is the problem that they do not stand up for themselves because the questions they want to ask may not lead to information that they want to accept, and as the interviews revealed where they had tried, they had been made to feel guilty and/or disregarded. In addition their focus was always on their loved one, for the informal carers, dealing with their (the loved one's) needs before their own had become second nature. Nevertheless, it was not acceptable that so many had been left with a sense of guilt, sometimes even a sense of betrayal, just because they thought longingly of the past

> *of the life we had…. She was… well of course she still is my partner … we chose each other for life… but Oh… I do miss what we had*

They repeatedly said they had a sense frustration, but accepted that to others it could appear negative, when in their eyes it wasn't. The findings left unanswered the questions of how they could ask for support, when they felt so selfish wanting something for themselves, and if they did ask, what could they ask for when they did not know what was available. Many were still struggling to work out *'what it's all about*' and until they understood what was happening how they could decide what they wanted their role to be. They were too busy just *'getting on with it'* to have time to stop and think, a sad reflection on what they had received in terms of support and help from what is internationally regarded as a good and efficient mental health service.

These informal carers reporting on taking little time to care for themselves but felt there was no other way to continue. However, there is evidence that this approach increases the numbers where institutionalisation of those dementia occurs because the carer is too exhausted to continue (Meiland F. 2002) and literally *'I am afraid I will just fall down and they take him away …I can't bear thinking about it…'* Nationally, since the initial government survey in 2011, the share of the group of informal caregivers who feel "fairly heavily burdened" has been stable amongst the four in ten informal caregivers who care for someone close with dementia (36% in 2011 and 38% in both 2013 and 2016). However, the proportion of informal carers who feel "very heavily taxed" or "overburdened" is slowly increasing with each repeated survey (from 10% in 2011, via 13% in 2013, to 16% in 2016). More than one in six caregivers felt "very heavily taxed" (12%) or "overburdened" (4%) in 2016 (Dementiemonitor Mantelzorg 2016). These findings were certainly reflected in this study, but the challenge is that despite these regularly repeated results, nothing has happened. There has been no major change in provision a situation that urgently needs addressing, this study had to develop a framework and model that could be submitted to government and used locally and nationally to start to bring about change or the view of the interviewee given below will become more and more prevalent and start to become a reality

> ***Do you know what I would like to do? Close the door behind me and never come back here. But of course, that is not possible. Who should take care***

of my mother? But I would like to like it ...... sometimes... (Emotional support)

The financial resources required are sometimes not sufficient either in insurance terms or national support as the incidence and prevalence rise. As a result, professional support, however necessary, is not automatically offered, and every extra type of help has to be fought for, and in some instances paid for, by the carer or their family. Caregivers of people with dementia belong almost without exception to the group of carers who are struggling the most, and the majority don't know that they can ask local government for support. In their turn, the local government however is not making things easier for the carers, their response to requests for help currently tend to be judged not on the fact that they are informal carer who are asking, but only on the financial cost of the request, with the result that the answer appears too often to be 'no'.

5.14.2: Respite care

Respite care is the collective name for various forms of care replacement. At home or abroad, offered by family, volunteers or professionals, financed from own resources, by the health insurer, the Wlz or the Wmo. The takeover of care may be incidental, for example during a holiday, but it may also be about a weekly weekday or monthly weekends. That variety is Respite care is a temporary and complete takeover of care with the aim of giving the carer a respite. (De Bruin en Kruiswijk 2013) Caregivers can care longer if they can take care of themselves and gain new energy themselves. (De Boer en van Kampen 2009) Caregivers provide care for those in need within their immediate vicinity. About three quarters of all care is not professional but family care, and therefore family care is an important fundament in our care system.

5.14.2.1: Need for respiratory care

Of the 1.7 million carers in the Netherlands who care for someone with severe congestion, one in four needs respiratory care (De Boer et al., 2009). That caregivers care for respite, a respite, is not a luxury but vital. Respiratory care not only aims to monitor the welfare of the mantle carer, but is also likely to contribute to goals at the macro level. Respiratory care is a collective term that encompasses different types of care. It forms an important part of the basic functions of local support for mantel care, which help municipalities to support local mantle careers. As decentralisation of extramural guidance and short-term stay continues, respite care becomes increasingly responsible for municipalities.

Care can be taken by family, volunteers and / or occupational forces. Volunteers provide respite care in a variety of ways. As a babysitter at home, as a holiday substitute, by watching a severely ill at night by assisting a daycare in a healthcare facility, providing suitable transportation to a care farm, accompanying holiday or cooking in a hospice or accommodation . Occupational careers provide respite care in day care, lodging homes, but also by keeping home while the mantle care worker is equally free. Or they coordinate the volunteers who provide respite care. Increasingly mixed forms arise in which occupational forces and volunteers give consideration to caregivers. This has already been said earlier.

5.14.2.2: Respite care can be at home or outdoors

The care can be given at home, but also outdoors. At home, respite care may include playing with a disabled child, supervising someone with dementia, or watching someone in the final life phase. Respite care facilities outdoors, for example, can be going to a care or nursing home facility for a period of time or it can be in the form of going for a walk with the assistance of a volunteer. This will allow the carer to recharge their 'batteries' and take some time for themselves. Time that they need badly if they want to continue the care for a long period.

> *I just have to be there every day 24 hours, the care for my husband never stops....*
> *(Experiences)*

As in the 2013 survey, more than a third of the participants take care of their relative day and night (32%). A fifth takes care of their relative "daily" (21%). 35% of the informal caregivers provide 20 hours or more of care per week, 24% even provide 40 hours or more of care per week. Informal caregivers of relatives living alone and close relatives in a care institution most often take care of their loved ones 1 to 6 times a week (56% and 61% of these groups of informal caregivers respectively). Informal caregivers (often the partners) of cohabiting people report the highest actual care burden as the majority of these caregivers (82%) continuously or daily take care of their relative. Moreover, 60% of them take care of their relative 20 hours a week or more, of which 43% even 40 hours a week or more (Dementiemonitor Mantelzorg 2016).

There is much need for multiple and varied forms of respite care, which can allow the carer to have time for themselves and feel confident that they are leaving their relative in the safe hand of the healthcare worker. Participants indicated that the types of respite care currently available do not provide sufficient answers to the wide range of support needed. There is a need for more forms of respite care that is 'tailored' to an individual's needs (Sociaal en Cultureel

Planbureau 2015, p 129).When discussing respite care with the carers they told me that their relative would not have had to go to a nursing home permanently, if they had another choice. There are several reports written on the subject of respite care in the Netherlands (Neville et al.2015). None of these reports are about care sharing, a new form of respite care in which the person with a disability is living in a nursing home for a certain period in a month. They share the same room and the care with other people and as collective they will utilise a single place in a nursing home. The carer provides the care in the period in which the relative stays home. Here too, the carer must first be aware of their own position and role and based on a form of respite care that fits the need of the caregiver at the time. After that, it is possible to search for other concrete solutions and possibilities that are available.

Informal caregivers have a great need for respite care, but do not know enough about the possibilities. They also often come up against practical barriers. This appears from recent research by the National Informal Care Panel. The group that did not use respite care in 2016 certainly needed respite (71%), but many caregivers are insufficiently aware of the options (20%) or they experience bureaucracy and red tape when finding and arranging a suitable respite facility (17%) or suitable volunteers in the neighbourhood (11%). In other cases the care appears to be difficult to transfer, or the relatives does not want someone else to take over the care temporarily (29%). Almost half of the informal caregivers surveyed are not sure whether they can transfer care acutely, for example if they are sick. This increases the burden they experience (Mezzo voor mantelzorgers, 2016).

5.14.3: Information

The lack of information given to the informal carers was mentioned throughout the data collection process and needed to be urgently addressed. It is became clear that the carers wanted to take care of their loved one, but they were requiring more support but were not sure how to access it. Without this information, the carers do not know that are entitled to support themselves. Only then can they look to access the most appropriate form of support for them for a specific period in their lives and that is accessible in the town in which they live. Carers look for information in all kinds of different ways and in all kinds of different places. The support often comes from different angles and is based on coincidence rather than targeted support. This can lead to support that is not specific to that individual, a one size fits all approach and not that of choice. Therefore, carers urgently need information that they can use immediately. The information be targeted at this individual’s specific needs in their role as a carer. This then gives the individual ownership of their requirements and allows the possibility to look at the various support options in their own environment and allow them to make a conscious choice.

Information can be addressed directly to the individual carer, but also has a more general and indirect function. Information to a wide audience about family helps to raise awareness about recognition of family care and the importance of support. The basic function consists of:

- Inform about family care
- Information about diseases, conditions, restrictions, disabilities and patient associations
- Inform about the offer of assistance, support, care (facilities and providers)
- Inform about legislation and regulations

Local governments can provide information on custody care in the (Wmo or local area). Caregivers can also be accessed through support centres or volunteer organisations. People often do not recognise themselves as carers. When they do then, easy reachable forms of information that are useful become available. For example, regular messages in local papers or in the local home-by-home newspaper. Digital information, for example in the social map of the region can also have a wide range.

> ***I had no idea where I should start looking for help or support. I was just busy taking care of my partner ... (Wishes for myself)***

Most caregivers (98-99%) experience problems in caring for someone with dementia, regardless of the stage of the disease process (NIVEL 2016). They have a need for advice and information, whatever the stage of dementia their relative is. In the early stages, carers often have difficulty dealing with the behavioural changes of the person with dementia; they want advice on the possibilities of professional assistance in care and tips for dealing with the patient's behavioural problems as well as more information about the course of the dementia disease. Despite the delivery of high quality informal care, carers of relatives with dementia often enquire about admission to a nursing or care home (Dementiemonitor Mantelzorg 2016).

There is a great need for better and more adequate information and the information must be available straight away. At least since the diagnosis is accurate information necessary and desirable. The caregiver does not know - or not good enough where support can be achieved. Not well informed means an extra burden for the caregiver because then feel all alone in the caregiving. Carers experience it as a trip where you do not know where to go and therefore do not know what to include in your luggage.

Most caregivers realise that their loved ones will deteriorate during the disease process, but are frightened by this concept. They fear a sudden relapse or the fact that their partner or parent becomes even more forgetful and will no longer recognise them or become zombie like and languish in a nursing home. Admission to a nursing home is a big concern for caregivers as they are afraid that their partner or parent will not be well cared for and will be left alone. They try to cope with maintaining care as long as possible in order to prevent admission (Stichting praten over gezondheid 2013).

> ***I had no idea what kind of disease was the cause that my mother became Alzheimer***
> ***. Now, I know that all these diseases have their own course. It would have been a lot easier for me if I had the right information on time... (Wishes for myself)***

There is so much information available that the information given must be informative 'customised'. Information that fits the information needs of that particular mantle carrier in a specific situation. Someone who has heard that the partner has the diagnosis dementia will initially need information about the phenomenon of dementia; Information about the disease. Carers sometimes have problems finding that informative.

> ***I really had no idea where I should start looking for information..(technical support)***

Immediately at the diagnosis of dementia, there must be sufficient attention for the mantle caregiver. There are two important issues:

- Where is there any information about the disease, course and treatment options and the support available in that area
- What does dementia mean to the caregiver? What position does the carer get and what does the carer want or can do with his own network?

If you do not know that you are a caretaker, it is hard to find the right information. There is a lack of view of the situation, the position of informal caregiver. Caregivers, who are not aware of their own situation, or not aware of their own circumstances, focus almost exclusively on the care for their loved ones with dementia. They categorise themselves as it were, spend no or too little attention on their own role as mantle caregiver. Search for information about care has only been addressed after sufficient information has been found about dementia. Your own position is subordinate to the disease and / or restriction of the person you are taking care of.

> ***The first half of the year after diagnosis, we did not really do anything ... .. seeking information and no help. We were as petrified after the message my partner had Alzheimer's. But there was also nobody who had helped us to do something, and I did not know where to start. I wish now I would have looked for many more support, looked for much more information .. If only had known ....(technical support)***

5.14.4 Recognition and support (Wie doet er wat? SCP Informele zorg 2015)

Psychology distinguishes between intrinsic and extrinsic motives (Ryan and Deci 2000). That intrinsic motivations are of importance to carers, according to previous research: for many people, caring is the most common thing in the world, they like to help the caregiver (De Boer and Schyns 2014). For example, they say they help relatives and acquaintances because they like to do that for the person or for granted. One in four reports that they help because they like it. In addition, extrinsic reasons play a role in caregivers, ie the motives that are triggered by external factors. The first type of extrinsic reason is aimed at postponing or preventing professional care. 17% report this as a driving force. Unknown is what type of care is prevented and what exactly the reason is. It may involve preventing or postponing admission to a care institution or extramural care. It may also be that the caregiver does not want to turn on any other caregivers or that the needy does not want any help from strangers. The second type of extrinsic reason is that the mantle sorcerer feels the most appropriate person. It may be that the person in need will preferably be helped by the interviewer (33%), or no-one else available (18%). The last motive has not been requested. We do not know where the absence of other helpers results. In this case, the mantle caregiver helps help because someone else wants it or because he has the feeling of helping. About one in ten caregivers feel "obliged" to help. This group reports both that the needy wants to be helped by the mantle career and that they help because no one else is available.

> ***I think it's just like that. In the past my parents took care of me and now I take care of them...... (Motives)***

Am I a family carer? This question is often asked by caregivers. Many caregivers do not see themselves as caregivers. Take care of your child, your partner, father or mother is quite ordinary? Especially young people do not speak the term carer at all. Citizens from other countries do not recognize themselves and speak more about family care. That does not make it easier to reach them. One of the problems for governments and policymakers in determining maternity care policy is that caregivers are not always registered anywhere, so they are difficult to approach to ask for their wishes. The major challenge for caregivers, such as caregivers, is finding ways to reach caregivers. There are many types of carers. Some are easily overlooked.

For example: the young child who helps her dementing father dress up by making ready-made clothes. The basic functions of mantle care often carry out unconsciously in practice and goes to the store with him. Or an older woman who helps her dementing man.

Carers do not often experience a problem for which they are going to find a solution. One of the main disadvantages of the support is that caregivers do not soon get a support question, a question of support. Even if they are asked directly if they need help, they will often deny it. They do not themselves see that they are overloaded. That has several causes. They have grown in the situation, care 'just happens’, take care of course, dare not to ask for help or do not know where to look for support. Carers will seek help for the patient rather than for themselves. Also, the patient may not want professional help. In many situations, even overloaded caregivers do not even ask for concrete questions about support. Certain symptoms may indicate overload, such as fatigue, depression and health problems. These symptoms are also not always recognized by professional healthcare professionals as related to mantis care. While one informal carer flies through life, another path falls into a depression or is strained because the balance between 'bear burden' and 'carrying capacity' is sought. In other words, the informal carer becomes overloaded. It is difficult to objectively determine whether there is a risk of overload, but there are a number of factors that are known to increase the risk.

These are:

Features of the carer such as age, health, competence, income and other activities besides caring (pays or voluntary work). Familycare is getting worse if the caregiver himself is badly injured, has a heavy job or lack of money.
Characteristics of the care provider. One patient needs more from a caretaker than another: Is the patient demanding and never satisfied? Is the carer depressed or very excited? Nature and duration of conditions and constraints can also play a role.
Features of the relationship patient and mantle carer. Can caregiver and caretaker handle the unequal positions in which they are? Is it a terminal sick? How much care can the patient give himself? If the caregiver is actually the only one in the patient’s life and the caregiver has no one to lean on, the risk of overload is high. These caregivers are called 'central carers'.
The living situation of carer and caregiver also plays a role. Do the patient and the carer live in the same house or far away? Allows the living situation that the carer can also lead his own life?

The presence of a network that can alleviate the burden and distribute care tasks. Is it with voluntary or occupational care / help? Is the help flexible? Good cooperation and alignment with voluntary or occupational care / help make a world of difference.

In particular, people who provide long-term and intensive care, such as caregivers of people with dementia, are at greater risk of overload. In addition to the risk factors mentioned above, risk groups can also be named. For example, 75-plus people who care for their partner almost voluntarily threaten to get exhausted. Also because they often have health problems themselves. It takes additional effort to reach this target and provide appropriate assistance. Young caregivers are at risk of compromising their education and personal development. Custom communication and free time to do other things than worry. The approach of the age group under the age of 20, the young caregivers, calls for connection with their lifestyle and communication tools, adapted activities and contact with peers. Potentially conflicting policies In VWS's policy, the right to social participation of the informal carer has to be recognised. Caregivers should be able to continue working and be able to send their family, the newspaper and the free time. The recognition is among other things in stimulating respite care, or the award of a so-called "mantel care compliment". **Family care is always voluntary and non-enforceable is the starting point**. This is in contrast to a newly created policy category 'usual care', the care that housewives can give each other reasonably. In the case of usual care, it involves short-term (less than three months) take-over of housekeeping and care tasks by housemates, for example after surgery. The different policies do not match each other. On the one hand, freedom of choice and volunteering of the mantle carer is paramount. On the other hand, counsellors have the task of indicating efficiently and efficiently in order to minimize claims for WLZ care. Increasing healthcare costs and scarcity to Wlz make it possible to make a more economical distribution. The Conventional Care protocol fulfils a gateway function and sets a dividing line between indivisible and non-indivisible care. The attendance of housemates is a part of the assessment of care due to the fact that they cannot get professional help for tasks that fall under the concept of 'common concern'. The explicit appeal to WMO's own responsibility in the Wmo is also at odds with the objective of the employment policy to substantially increase the employment of women and the elderly. Women and fifty-two are the largest providers of care services.

And in the new reality of disparate laws and regulations that sometimes also contain contradictions, the caregiver is also not always recognized in this term. Awareness of their own position and role together with strengthening their own strength and self-reliance provide opportunities for a substantial improvement in the position of people who care for their loved ones.

5.14.5 Carers must become fully respected partners in care

(SOFA model, Movisie 2017)

Carers need recognition and support, mentally and in a concrete offer. They may be, must be experts for professional care providers. They see themselves often as experts, however they have a marginal place I a care process.

> ***I wished there was a better contact with the professional care……..(wishes for myself)***

The majority of caregivers who provide help with home care professionals or nurses believe that they are treated seriously. They are however less satisfied with the decision-making and sharing of aid: almost half of the carers believe that they are not able to decide whether or not to share the care activities well. More than half, home care professionals or district nurses do not have enough insight into how it works with the mantle caregiver. Carers of people with a psychological / psychosocial problem are least pleased with the cooperation. (Wie doet er wat? SCP 2015)

The informal care: care and the use of respite services for example, should be given an important place in the care record. Not only the care record of the patient with dementia but the care record of the family unit: all persons residing in the same household and those involved. There should be a care – and support dossier for the living unit as total.

5.14.6 Technical support is hardly used at the moment, but has potential

With regard to the use of technology, there is still a world to win. Sometimes the Internet is used to search for information. The huge amount of potential opportunities that can offer the technology such as home automation and online instruction videos and information for carers are not much used and certainly not used as support. Carers say that they can imagine a certain support based on technic but they just don't know what (potential) possibilities there are. There is certainly no objection for using technic by carers.

> ***I think technology could help me but I do not really know how that could be. I'm definitely not negative about that... (Technical support)***

Chapter 6: Development and implementationof the Model

6.1: Introduction

Looking back at chapters 5, it was apparent that the wealth of data that emerged as the project progressed needed to be combined to facilitate the development of one integrated approach as used to form a basis from which to build a full service to support informal carers. As the findings indicate, some of the experiences of the participants were such that an immediate rsponse was seen as essential. This led to the design, development and implementation of a series of individual projects as the project progressed. All of these, with their emphasis on enabling individuals to seek help for themselves, were established using strategies that supported sustainability. Although in actuality, these were initiated sequentially with different aims and outputs, they all impacted on, and facilitated, the development and refinement of the model. Ro present the model indicating where the individual activities started is difficult. Therefore, for clarity the development of the model is described in this chapter with the projects and national outcomes presented in chapters 7 and 8.

The model developed needed to fit with the WMO (2007; 2015) changes in government policy, therefore, a major focus had to be on facilitating access to services and enabling individuals to seek out help for themselves. As the policy changes were designed so that the community would take on more responsibility for itself, all activities were designed as partnerships with service users (in this case the informal carers), with the aim of gradually handing contorl over to them. Strategies of empowerment (Wakefield, Bayly, Selman et al 2016) were used to strengthen and enhance participants' sense of self, and through that their self-confidence, as only then would they be able to interact with health professionals to gain the services they needed for themselves and their loved one (WHO 2009; Angelmar and Bermann 2007; Bravo, et al 2015). WHO (2009) described empowerment 'as a process through which people gain greater control over decisions and actions affecting their health', and since then this definition has become a cornerstone for the development of national and international health policies and strategies for implementation.

6.2: Building the model

According to the WHO (2009), there are four components fundamental to the process of empowerment needed to enable informal carers, and their loved ones to access the help and support they need. Firstly, the individual needs a clear understanding of their role and the expectations of both family members and professionals (Hibbard and Gilburt 2017), in this study, the informal carers had embarked upon a caring role, believing that they understood what would happen. However, the dementia trajectory had proved to be very different to their expectations, and because for most, the changes had '*happened slowly… I didn't realise what* *was happening…'* the interviews revealed that many, had only realised late in the process how their lives had been changed and that *'I have no time … none at all for me'*. However, despite this realisation few had actively considered what exactly their situation had become, hence the need for the Alzheimer's cafes and day centres, and the decision to develop the carers' video and tool kit.

Secondly they need sufficient knowledge to be able to engage with healthcare professionals (Hibbard and Gilburt 2017; Wong, et al 2014). They had focused on trying to find out about the disease trajectory of the type of dementia their loved one has, *' I tried … you can't have too much information…. but working out what it all meant….well…'* but as this quote illustrates, it was evident that many did not fully understand the implications of dementia. Research into available information made their responses understandable, much of what exists is either couched in medical terminology, hard for the lay person to follow, or anecdotal, based on individual perceptions and experiences (Dixon-Wood et al 2006; Wakefield et al 2018) . This left the interviewees desperately trying to *'sort it out'.* The combination of gaps in knowledge in both patient and support services for carers was a somewhat daunting finding. It had resulted in the interviewees knowing what they believed was wanted and needed for their loved one, but with few understanding how to access care for themselves, a situation that the tool kit was designed to address. However, as comments such as 'I *know I should … but there's so little time I need it all to look after xxx'* were typical, information on its own that would not be sufficient, the sense of guilt reported that arose in asking for something for themselves when *… it's so much worse for him…* had to be addressed before they felt comfortable enough to search the information for what they saw as '*selfish'* reasons. For others, guilt arose because they had not understood what was happening and looking back at how they had reacted to their loved one's changed behaviour haunted them '*the guilt…it never goes… I can't tell how sorry I am'* acted as a major constraint. In the light of what they saw as their failure to care appropriately, left them disinclined to ask *'for me… it's my responsibility … to care',* this group need time and support to accept what has happened before they too, can look to themselves.

Thirdly, they need skills in self-management and self-efficacy to be able to assess the appropriateness of what is available, and then negotiating skills to work with professionals to construct and appropriate care plan and supervise its implementation (McCorkle et al 2011; Wakefield et al 2018). They need to be confident enough to accept the role of professional into their family unit, as it is the healthcare professionals who know what is available, and under the Dutch system, there are formalised processes that only professionals can institute before services can be implemented. However, the study revealed that while they were adamant that they wanted to be seen as the *'expert'* in identifying what they partner/parent/child needed, they also need the skills to negotiate with this important group. Repeatedly, descriptions were given of friction in encounters with healthcare professionals. For some it had meant being offered what they saw as *'standard'* services, not *'tailor-made',* while for many others it seemed to them that that they '*always had to fight for services …'* and *'it's never easy… they don't listen…'* Negative perceptions of contact from when they had tried to access services, usually for their loved one and not for themselves had resulted in a belief that *'there's no point.. Nothing I want happens…'* Were compounded by those who felt they had had no support from their GPs.

The final component that of the presence of a facilitating environment is intrinsically linked to the relationship with the healthcare professionals. It is accepted that the healthcare professional has a different perspective, based on what services are possible, the costs of provision, and the needs (as they see it) of the individual (NHS England 2015). In this study this seemed to have led to a hierarchy, with the professional in a much higher and stronger position. The aim of the WMO (2007; 2015) was the change this situation, creating an environment that places client and professional on a more equal basis. They documentation states that new models of care need to be designed to empower patients and communities, much as described by NHS England (2015). However, for this to be possible, the professional has to recognise that their role has changed, moving from the traditional authorative stance to a more equal partnership with individuals, families and communities (WMO 2007). Traditionally their focus on the patient and not on the whole family will have impacted on how they view requests for support for informal carers.

Nationally all care organisations were informed that by the planned implementation of the WMO (2007) in 2015 service provers were to have implemented strategies changing their approach, with (as stated previously in chapter 2) , responsibility for informal carers. However, in this study, there was little reported evidence of any perceived change in approach reported by interviewees, and little evidence that in addition to patient needs, those of the informal carers had been accepted and included. It has to be accepted that the major paradigm shift in provision wanted by the Dutch government is difficult when employees are already in operating at full stretch and when the informal carers have such a negative attitude, openly saying that *I have had to learn…I'm on my own'* . Or when asked about asking for more help for themselves made comments such as *' I'm just too tired...*. Any proposed framework and model clearly has to address this, including strategies that recognise that every individual and family is different and that their capacity to cope and independence will vary (Jacobs et al 2015). Only when informal carers have the confidence that comes from empowerment will they be able to take more control over their own lives and through that gain increased acceptance of their role as an equal partner in care planning and service delivery for their loved one with dementia (Kwekkeboom & JagerVreugdenhil, 2009; Wakefield et al 2018). This view is supported by clients and patient support movements who argue that it is only through partnerships that recognise the position of carers, will sustained changes in care provision lead to a greater focus on the importance of social functioning and not just physical or cognitive dysfunction (Van Regenmortel, 2010).

All four contain components cited above, contain empowerment as an integral key to their achievement. The challenge for this project was to design a framework and model that incorporated these four components, fitted within current government structures and was flexible enough to incorporate the type of developments that had occurred during this project. There needed to be a Netherlands specific conceptual framework and model that could be used to support informal carers of all ages, with different needs and capabilities. The European Patients Forum (EPF) (2015), in their strategic plan 2014-2020 is one of the few to specifically consider the role of informal carers in care provision, aiming at using empowerment to give the control over their own and their loved one’s care. They argue there is a need to

> **‘Equip patients (and their informal caregivers whenever appropriate) with the capacity to participate in decisions;… to become “co-managers” of their condition in partnership with health professionals; and to develop …coping skills to manage the physical, emotional and social impacts of illness in everyday life.’ (EPF2015:5)**

This definition focuses on the individual, and EPF (2015:6) went on to include expand this to a more collective definition in which it is seen as a process which enables individuals, families and communities to learn to vocalise their needs and concerns in order to

> **Devise strategies for involvement in decision-making, and take political, social, and cultural action to meet those needs.”**

If combined with other theories, such as with patient activation (Hibbard et al 2004; Green and Hibbard 2012), these definitions could support development of a more comprehensive model. There is a wealth of research and literature discussing the importance of this concept in improving access to, take up of services and service outcomes (Wallestein 2006; Chatzimarkakis 2010; Selman et al 2016; Chen et al 2016). One of the most appropriate studies for this project was that by Chen, Mullins, Novak and Thomas (2016:2) who suggest that in health care, empowerment should be a:

> **Cyclical process defined through patient accumulation of knowledge, confidence, and self-determination for their own health and health care.**

They used this approach to develop P-PAE the culturally designed Personalised Patient Activation and Empowerment model, this is based on a series of interactions between the individual, the healthcare provider, the community and health care system structure. This was developed from a combination of theories including patient–centred outcomes research (Fleurence et al 2014, Selby, Beal and Frank 2012), social behaviour (Barr et al., 2003; Brownson et al., 2007) and shared decision-making frameworks (Sandman, Granger, Ekman, & Munthe, 2012; Légaré & Witteman, 2013). They argue that activation and empowerment are different but interdependent concepts. In their study patient activation refers to patients' knowledge skill and confidence to manage their own health. While empowerment is described as being more pro-active, involving self-efficacy, and the capacity to make informed, autonomous decisions about their own health. It puts the patient in the centre of the delivery system, providing a framework within which to analyse patient-professional actions, interactions and inter-relationships at all levels. Although designed for patients, looking at the way in which the model was developed, suggested that the concepts could be translated for use with informal carers in a situation where the patient has impaired cognition and, as in dementia, cannot always make appropriate decisions for themselves. Although, as with the EPF (2015) definitions, the P-PAE model did not fully address the questions raised in this study, nevertheless they both contributed to the final conceptual framework and model.

6.3: The paradigm shift

The current situation in care provision for dementia patients can be summarised as perceived by carers to be a linear system where as the role of the professional and the services they offer dominates service provision. They are the gatekeepers, and often tend to become involved only when the systems supporting the individual have failed, by then families have started to provide care '*I managed as long as I could…* and seek help for explanations of behaviour change, diagnosis and help to continue to deliver care. Support for informal carers has in their view been *'tacked on…an added extra'*. As the diagrammatic representation below indicates, for the interviewees, the professional role seemed large and authoritative, and, as the descriptions in previous chapters indicated, many of the informal carers felt powerless. They had to *'ask and ask… for help… for support'*. For the majority, it had not been an easy road, support had to be slow to come and often had not been what they wanted. Using their descriptions, the linear programme shows the informal carers and their families, paler and as shadows in comparison to the powerful professionals as one said *'I try… but they decide they are the ones… I can only ask',* and ultimately, as they state, their support is very limited.

Figure 6.1: The current situation

However, there is a further issue that needs to be considered and included when planning the conceptual framework and model. It is essential that any changes do not further adversely impact on the informal carers, to raise expectations that cannot be met would be unacceptable. Any new approach to service provision must fit within available resources, be sustainable and must address the perceived imbalance between the carers and the professionals. An increasing challenge is that across the country, the rising demand for health care is such that without partnerships that facilitate appropriate and effective use of health services, government estimates suggest the current health care system will not be able to cope with demand (Raad voor de Volksgezondheid & Zorg, 2010a & b). The consequences arising from economic slowdown in the Netherlands has impacted on the scope for growth in health care expenditure, in all areas, including recruitment and retention of qualified personnel (Raad voor de Volksgezondheid & Zorg, 2010a), a situation likely to be exacerbated by the major economic problems accompanying the current pandemic.

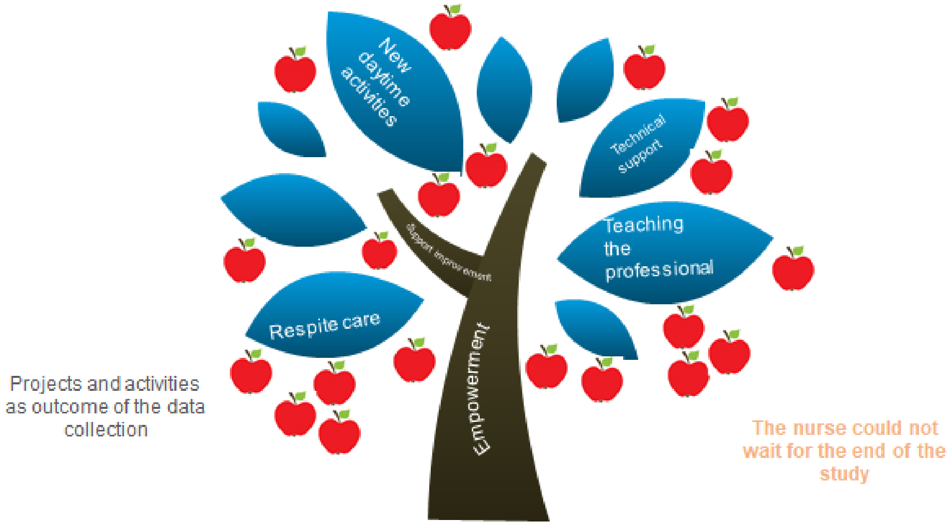
The government plan for reducing state involvement and thereby costs, through individuals taking responsibility for their own (health) situation, behaviour and for organizing as far as possible their own care and support systems did not seem to have been recognised by those participating in this study. The informal carers reported feeling *'let down…I need more support'* their expressed view was that they were *'struggling… it's too much'* had they been empowered and encouraged from the beginning their responses might have been different. However, this group who were already well down the road of caring, they wanted control in determining the services they received, and to take responsibility for the care of their loved one for themselves. They were keen to support each other, and help their peers as volunteers, but all saw the need for additional support services provided by statutory bodies. What they wanted was a major paradigm shift so that as indicated in the diagram below, the professional role becomes diminished, taking on the lesser role that currently they believe that they and their families have.

Figure 6.2: the new situation

They stated that the decreasing ability for self-care needs early acceptance and recognition, with help offered early. However, the biggest change is that as self-care decreases the role of informal carers is recognised as *'important… after all….I look after xxx…. I need … them* [professionals] *to respect me'.* As some pointed out *' what would happen if I wasn't there… if I couldn't cope'.* In reality, what happens when they cannot cope is clear, the largest reason for admissions into permanent care is exhaustion on the part of the informal carer. For the carers in this study, until the hierarchy changes with professionals taking a lesser role, they can only see that time coming more quickly, they have an ongoing *'difficult time… I don't know how long … I can carry on'*. Statements such as this, clearly illustrate one of the saddest elements of this study, the number of interviewees who believed they had failed the promises to, and in some cases the family bond they had with their loved one, but were determined to *'keep going… if I can'*. The challenge was to create a framework and model that could address their perceptions, and encompass as far as possible the type of services that would offer adequate support for the wholes family unit, and yet fit within the increasing financial constraints.

6.4: The first attempt to develop a model, the tree

An appropriate starting point it seemed to be to review and collate all the activities generated for each new road. To maintain transparency the participants had been kept informed of the project progress, and as each new activity arose, these too had been shared. In the initial discussions participants described increased activities that had attended or been involved in as being *'what I needed…'* However, as chapters five and six illustrate, each one initially started as a separate entity and while some activities contained common characteristics, in essence each of the new roads described followed its own route. As a core element of the whole study was empowerment, a way was sought to use this, to bring the activities together, that fitted with the feeling that the project had developed a life of its own. The first attempt, developed with participants was a tree, with the trunk representing the road as a rising path of empowerment, core findings represented as leaves, and the individual activities represented as fruit from the tree.



6.3:The first attempt: the tree

This pictorial version, when shared with other interviewees, and participants attending an Alzheimer's café was welcomed, they saw it as a *'positive'*, and for them clear representation of the outcomes of the activities. They saw this diagram as including the main issues they had raised, and reported that they particularly liked saw what they described as a *'large leaf'* for teaching the professionals. One of the most frequently reported concerns had been that the professionals did not understand what being an informal carer encompassed, and this leaf was seen as illustrating the need for education for health care professionals. They openly stated that it 'showed *what we want…'* It was an important shared activity, as it confirmed to them, that they had been heard and believed. It was developed in the light of the data, with interviewees, and it was possible to use it to illustrate each one of the roads. However, although members of each activity who saw it identified with the content and presentation, it was too limited. Although symbolically based round a 'living' tree, it was in essence static, did not join the separate roads, and nor did it offer a way to change policy and practice. Developing ths 'tree' had been a worthwhile exercise, it had clarified and confirmed the perceptions of the interviewees, which in turn was then used to support the development of the conceptual framework and model.

6.5: Looking for new and combined models

With all activities carefully collated, the next step was to consider how these could be linked together, and how individually and collectively they could be fitted together to generate a conceptual framework. The research had been designed around a specific theoretical framework which delineated the underpinning philosophical, epistemological, methodological stances, making explicit the processes for analysis and data usage (Ravich and Carl 2016).

The challenge was to utilise the findings and application of theoretical constructs to create a generative framework that gives insights and increased understanding into the phenomenon studied. Narrower than a theoretical framework, a conceptual framework focuses on specific concepts, ‘promoting and systemising’ emerging knowledge, to illustrate and describe possible relationships between key concepts (Dicksen, Hussein and Agyem 2018:439), supporting the identification and construction of a real world view (Grant and Osanloo 2014). Akintoye (2015) argues that they are of benefit when existing theories do not provide adequate explanations of data, or are not applicable. In qualitative studies, particularly those based on grounded theory, researchers incorporate both relevant theory and empirical research. These are used to organise datasets, identifying overlaps, contradictions, and where refinement and/or qualification of the findings are needed to ‘ground’ concepts within the data sets, and complete composition of an emerging conceptual framework (Rocco and Plakhotnik 2009). Once created, it can be used to reflect the outcomes of an entire research process, giving a new proposed construct for a model to explain social processes and interactions (Ravich and Carl 2016).

For this study, it was evident from the data that to improve the situation for carers, they needed to increase access to, an appropriateness of the services they received. The most appropriate way for them to do this was to use empowerment to enable them to gain the self-confidence to take more control, and to change the current hierarchical situation where they saw themselves at the best, as junior partners. Then too, in the light of the interviewees perceptions of the services they received, to move to the approach they wanted where the health care professional had a lesser role overall, a paradigm shift in service provision would be needed. However, this could only be achieved by working in partnership with healthcare providers, locally, regionally and nationally. As this study has indicated the whole premise of the WMO (2007) was to increase the role of informal carers and the community. They freely discuss the importance of empowering individuals, families and the community, but since the inception of the cahnges not additional funding has been released to help the planned changes be designed and implemented in practice. However, coordination between the various financial departments and insurers involved as a result of the Wmo (2007), the municipalities, the Long-term Care Act (Zorgkantoren) and home nursing (Health Insurance Act) is still in its infancy. The reality, is that there is still insufficient knowledge and guidance available to municipalities to hwlp them to set up informal care support services, let alone expand them to meet the increasing need. A second challenge is that the WMO (2007), gives every province the right to decide what theit own communities need in terms of informal support. The combination of lack of guidance, freedom to choose, and not additionla finacial help has led to disparate, fragmented services, with the informal carer desparately trying to *' find out... who to ask for* what' and confused as to why:

> *'everyone doesn't get the same... it says* [internet information] *I can ask for xxx... but when I tried they* [health professionals] *said we don't do that...*[in this province]' '

For the informal carers working out why they cannot have services that other areas offer, when they live in a country where they think there is a national insurance based service is incomprehensible. It is imposssible to answer the question *'why?...'* patient forums do their best, but they too have no answers for this anomaly in care. Equity of provision is essential is the WMO (2007) changes are to be effectively implemented across the Netherlands. Therefore any conceptual framework has to recognise this, as it aims to address the polices that have led to disparites in care services. For this, theories of change management have to be used to underpin and facilitate change and adaptation of services. These cannot be 'ad hoc' but should be a structured process of managing people, processes and approaches technology in response to the changing environment, in this case, changes in government policy. Teczke, Bespayeve and Bugubayeve (2017) argue that for this, managers and leaders should become role models, demonstrating what is needed and expected for the change process to succeed. Anyieni, Bcom, and Campus (2013) take this further suggesting that change management means planning, initiating, realizing, controlling and stabilizing the processes of change at both corporate and personal levels.

For this to be achieved, local governments need to stay in contact with all elements of informal care, family carers, professional services and care volounteers. Using these contacts to plan and deliver support services, owever, for this to be formalised and sustained, new policies will have to be developed integrating all aspects informal care at all levels. This new policy must be supported by guidelines and templates for delivery. The implementation of the WMO (2007/2015) demonstrated that without these, the local and regional authoriities did not on the whole, develop new local policies, strategies or processes to implement the government changes. The guidelines must indicate how the national policy can be translated for use by healthcare professionals, and care organisations, with examples of existing projects working at different levels, delivering support for informal carers and the organization of care volunteers. Only with clear and detailed information can the proposed changes in policy and practicies, plan, initiate, realise, lead and support stabilisation at all levels, from individual, through corporate to national systems (Anyeni, Bcom and Campus 2013). There are a plethora of different appraches to change management and systems for change since Lewin's (1947) seminal work was first expounded. His work has been built upon, adapted and revised, forming the basis for models developed over the decades, including the three step model (Newstom and Davis 1985) the four step model (Bullock and Batton,1985) and was for many years the most dominant approach to change (Todnem By 2005). Using these systems for change management of change was conceptualised either as a rational, strategic process in which a new course of action was chosen and the organisation or company adaptsed to the changes, or as an evolutionary processwhere individuals within the porganisation may well resist the changes, prventing them from being fully successfully implemented implemented without personnel changes (Hlood and Fennell 1995; Teczke, Bespayeva, and Bugubayeva, 2017). While Wiggins (2008) argues that problems arise from flawed plans or maps for the total change, which leads to misunderstandings, resistance, and misuse of knowledge, with change management seen as ‘ad hoc’. Instead it needs meticulouse planning with structured processes for managing people, processes and procedures aligned to the changing environment.

Teczke, Bespayeva, and Bugubayeva (2017:195) acknowledged the wide range of views and approaches, their review and analysis of mdoels concludes that there is no one ‘best approach, but that study of the area and rationale for change should be used to identify the way forward. They suggest that the nature of changes proposed can described by the principles of temporal change, and outline two distinct apporaches. Using their work, then the WMO (2007/ 2015) used ‘changes as a constant part of the component’ (Teczke, Bespayeva, and Bugubayeva 2017:200). This is based on the belief that the organisation’s members are willing to change and will develop the necessary ability and skills, with the changes seen as continuous, without time limits. This approach is designed for long-term development of the system as a whole and not a single solution, and is seen as an investment in human resources. This description fits well with the stated aims of the WMO (2007), with its general statements that the community must take more responsibility for itself, and that individuals need to assume responsibility for their own health. The documentation makes it clear that underlying the policies is a bekiefe that this approach would be welcomed by the community as they have long wanted ‘more control’ over the services they receive. Also that the provinces and local autghorieis have argued for more localised services, and by devolving care, it will be possible to move forward positively and implement the planned service revision. However, as described earlier, this did not happen, instead the gap between the govenrment and the lcoal services providers was too great, and there was a lack of connection between the different agencies, patients and their families. As a result, the lack of progress between 2007 and 2015 was missed, different groups developed in different directions and sustainable changes did not occur, resulting in the Durch government urgently seeking for a way to resolve the mismatch between service needs, patient expectations and service provision.

Looking at the findings from this study, it seemed that the alternative approach suggested by Teczke, Bespayeva, and Bugubayeva (2017:200) whereby the changes are viewed 'as a project'. Using this, the changes would been seenas a major one time change with a clearly defined start and end dates by which time clear and transparent outputs should have been achieved. This approach fitted well with the decision that guidelines, templates and outputs needed to be meticulously described. This would upport the design and implementation of major changes including restructuring of services, as originally described in the WMO (2007), where the government openly encouraged a participatory society. It recognises that Informal care is, in addition to professional care, indispensable for many people who need help and care. It accepts the need for changes in role and where necessary mergers between stakeholders, and focuses on crucial management activities. The challenge was that for this to be successful a model for change needed to be developed that prevented a gap arising between government strategy and lcoal initiatives. In the light of the four components of empowerment, the starting point for the development of the model was clear. Strategies had to be developed to guide activities, with, as had been originally planned, members of the community slowly taking more control, until as illustrated in figure x, the services to infromal carers were the strongest element, with the professionals handing back authority to the informal carers and their families.

The data sets had revealed that with dementia, care needs change constantly, and that current service provision is not responsive to change, or to the informal carer deciding what is needed. The comment that

> '*I am the expert…Not them… they see him for a few minutes…. I am there 24/7…*
> *no one accepts that I am the best one know what he needs….I should decide…'*

This clearly expresses how the informal carers felt, and the resentment that arose when they had to '*fight'* for increased or enhanced service provision. It also highlights the need to include the whole family in the diagnosis. Had this happened, confusion and the belief that they received inappropriate services would have been reduced or avoided. Working towards participation and empowerment can help change the traditional power structure between patient, carer and care provider (Jacobs, 2008). This in turn helps move towards demand-driven or better still, dialogue-driven care, which would address many of the concerns cited in this study (Van Regenmortel 2009). Looking at the data sets from the perspective of the informal carers, several aspects of empowerment were identified that contribute to mutual relationships can impact on practice and therefore need consideration. These included, informal carer self-identity, experiential expertise, participation, and empowerment for the whole family unit.

Looking at self-identity and how it fitted into the model, the data demonstrated that the carers had repeatedly given statements which indicate loss of self-identity. Most reported not receiving the respect of the professionals, nor being acknowledged for what they did, and being excluded from medical decisions regarding their loved one, also they felt disregarded, and '*not valued…'* Yet these are all part of self-esteem and integral elements of empowerment (Selman. Daveson, Smith et al 2016; Richardson, Macleod and Kent, 2017; Chatzimarkakis, 2010). For them to become confident enough to take control of their life and that of their loved one, ways needed to be found to increase explicit recognition of their importance in enabling those with dementia to stay in the community rather than be admitted to full institutional care, into unfamiliar settings and separated from their families. A review of approaches, conceptual frameworks and models for empowerment revealed that in healthcare, these have been developed for patients, and not for their informal carers. However, the conceptual framework developed by Wakefield, Bayly, Selman, Firth, Higginson and Murtagh (2018:1297), although designed for patients with life limiting illness contained concepts that could be modified and translated for use with informal carers of those with dementia.

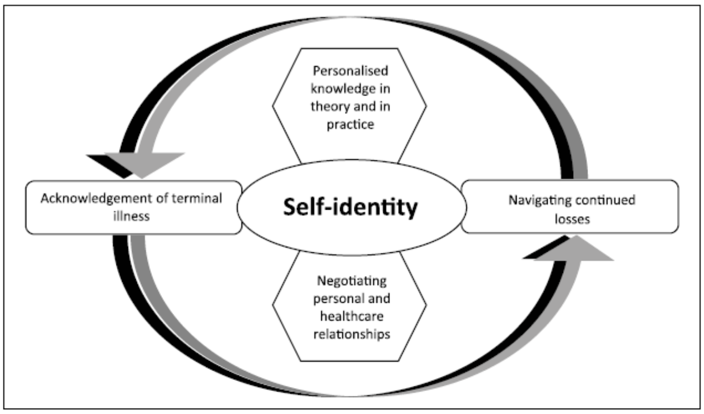


Figure 6.4 Wakefield et al's (2018:1297) conceptual framework for patient empowerment for adults with advanced life-limiting illness

The two encompassing concepts have clear parallels with the data sets in this study. The 'acknowledgement of terminal illness', which for the informal carers translates to acknowledgement of the disease trajectory for dementia. This had taken time and not been easy, because

> '*I knew nothing about dementia… I couldn't take it in... there had to be something they* [healthcare professionals] *could do… we had so many plans… just gone'*

While ‘navigating continued loss’, fits with the loss and grief that arises as the disease progresses and the informal carers watch their loved one *‘slowly fade …’* until as some said *‘s/he’s gone…. The body is left, but xxx has gone…’*

The central issues all fitted with the data sets and the needs that had been identified for ‘*more knowledge’* and *‘ the problems I have getting help…making them* [healthcare professionals] *listen’* . Every effort had been made to address these with the individual projects and activities that had arisen as the project progressed. In each of these there had been a focus on increasing access to appropriate information given by the informal carers, and to helping the informal carers learn how to navigate the health care organisations, increasing access and support both for themselves and for their loved one. As the projects developed and individual activities grew exponentially, over time, changes in the attitudes and confidence of the informal carers, became more evident, contributing to an increased sense of worth. This conceptual framework with its focus on listening rather than doing, re-enforcing equality and engaging with patients was both appropriate and practical. Empowerment of the informal carers worked through an approach in which the sharing of information (knowledge input), dialogue and a different way of providing care was central, using a combination of listening and giving attention, sharing information and questions, helping them to dare to learn from others, creating space for democratic consultation and sharing and explicating responsibilities (Reinhard et al)

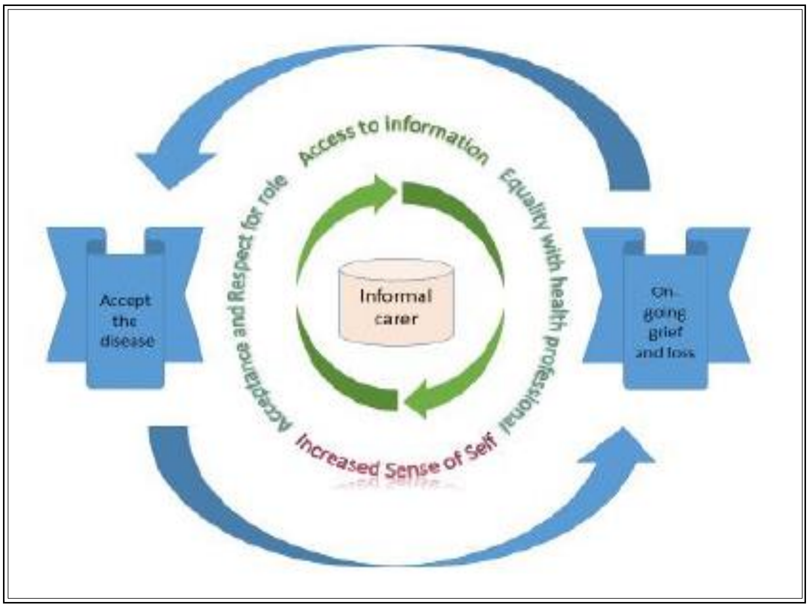


Figure 6.5: Model for empowerment designed for informal carers

The concepts included in the model emerged from within the data sets. Each one of these has its own strategies and mechanisms for implementation, which in combination can facilitate the process of empowerment. Informal carers are key players in the implementation of service provision, and the maintenance of the family unit, and therefore the model was initially designed to meet their needs, but this was just the first element of the overall conceptual framework and model. While the model was appropriate for individual participants, the whole ethos behind the project was based on the recognition that it was the whole family unit that needed support. Therefore, to meet the aims of the study, it needed to be adapted, to enable support to be offered to all those identified as part of the family, recognising that each individual has their own specific support needs. The concepts used in the model for informal carers are appropriate for all family members, and it was therefore decided that the only change needed was the move from individual to family unit. In consequence the central figure was changed to encompass the family unit offering a model of personal empowerment that fits with policy vision of the Ministry of Health, Welfare and Sport (MinVWS 2020).

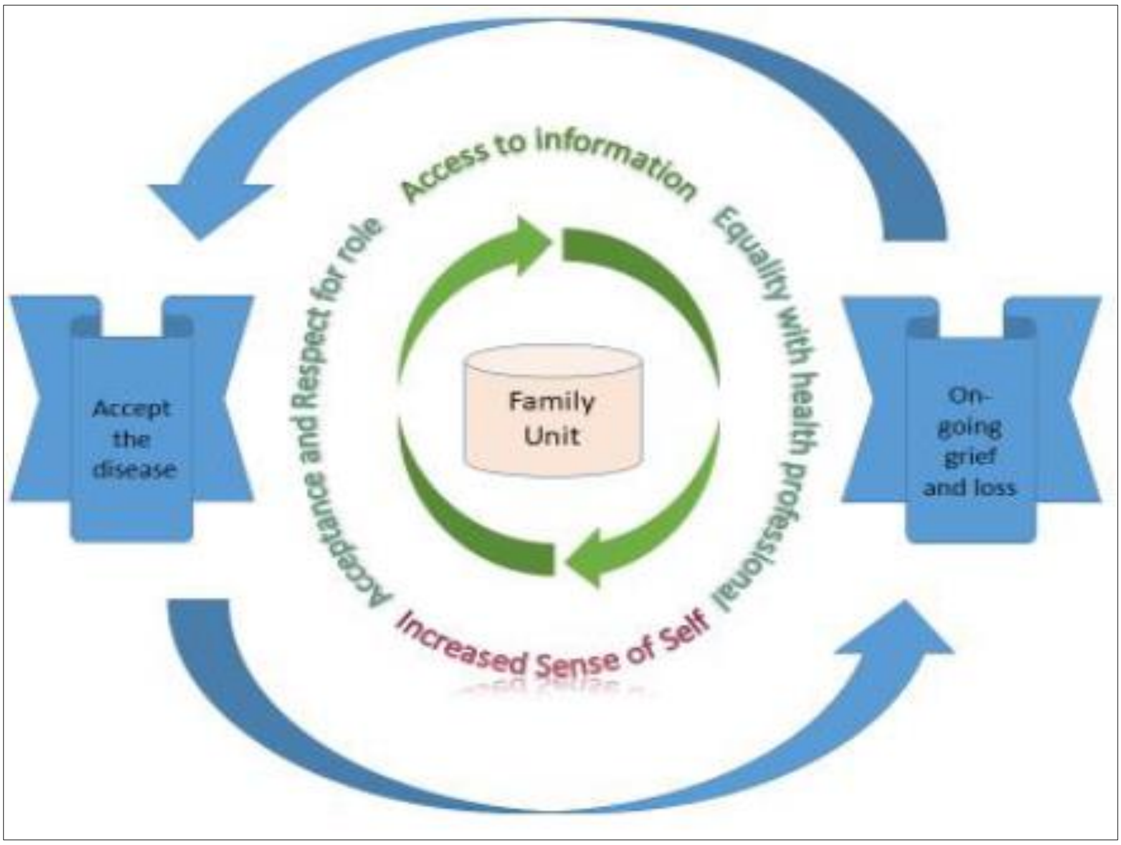


Figure 6.6: Completed Model for Empowerment for the family unit

The challenge was that this model of empowerment was designed to support individuals within the family unit, and therefore needed to be an integral element of the overall conceptual framework, but it was not designed to facilitate changes at corporate or national level. Therefore further development was needed, on a meso and macro level to support changes at local and national policy level. There needed to be a change in approach, which the individual model worked from the individual and family unit outwards, the overall conceptual framework and model needed to fit with local and natonal policies, and with the unique healthcare system operating in the Netherlands. All recommendations needed to be designed to support, and not conflict with government structures, so were dependent on the context of the changes which began with WMO (2007) and followed the implementation strategies described within the in WMO (2015).

6.6: Application of the model for empowerment for the family unit

The next taskwas to review again the documentation and to contact the Ministry of Health Wellbeing and Sport. The implementation of the WMO (2007) has already been delayed for more that a decade, during which time there have been considerable health, economic and social changes. In consequence a change model was needed where implementation could being rapidly, with outputs being incrementally developed and implemented. The literature reviewed that focused on change managment at corporate level. Much as with previous government documentation discussed principles and plans, but gave very few detailed guidelines or practical ways forward. It was essential that the mistakes that arose from treating implementation as a continuous process did not occur again. It was important to note that the decision to change to use a project approach does have the risk of timescales being inadequate, which can lead to disconnect between providers and users not being able to be addressed in sufficient detail in the time available.

The Dutch government had wanted 'customisation' (WMO 2015), but had to accept that while they thought strategically, provinces and local authorities focused more on the direct needs of their communities. The result had been that at these levles officals had chosen to continue with what was already running, rather than risk the innovation needed, on the gounds that they had insufficient information, few guidelines and no additional finance (see chapter 2). In addition as Jacobs, Hagenaars and van der Veer (2015) pointed out, non of the models had been developed for non-profit organisations at national level, and there is a major diffeence between business and profit seeking organisations and the nature of the not for profit health service. They suggested that Kotter's (1995) eight step model was appropriate, but in the 25 years since that was developed, the societal and health contexts have developed beyond belief, with medical advances and increasingly complex health systems. Thus the gap between theory and practice is even greater here that the gap between the design of the WMO(2007) and its implementation (WMO 2015).

It is accepted that care providers are, and need to be, at the forefront of any new developments that can bring about change, but few have been given any opportunity to extend their change management expertise, or specific guidelines on how to lead change (NHS. 2018. The Change Model Guide) In consequence in their review, little sense of urgency was found among those who would have to lead the changes (Jaap, 2013). This may in part be because as Jaap

(2013) points out some models developed appeared to be exercises in extending bureaucracy, for example, the development of a system for 'Change management in 28 lessons' something that not surprisingly, few were keen to consider. For change managment to be successful, there has to be a willingness for change, and the actions proposed need to appear realistic, appropriate and practical (Teczke, Bespareva and Bugubayeva 2017). Looking at possible models, that could work using the project approach, it seemed that as several studies on the Netherlands had highlighted the use of clearly described step-by-step models, a framework using this approach was likely to be accessible and acceptable to healthcare professionals. Lookinf dor models that work in this way, one of the ebsr known is Kotter’s (1995), eight steps were reviewed (see table x) to assess their suitability as a basis from which to build.

Kotter (1995) the 8 steps for managing change

- Establishing a sense of urgency,
- Creating a guiding coalition,
- Developing a vision and strategy,
- Communicating the change vision,
- Empowering employees for broad-based action,
- Generating short-term wins,
- Consolidating gains and producing more change,
- Anchoring new approaches in the culture

Table 6.7 Kotter 8 step model

Research into use of Kotter’s (1995) model, revealed that it has been identified for use in the Netherlands as suitable for promoting change in Dutch hospitals. However, while in principle the model had been seen as appropriate, challenges and difficulties had emerged with its application, particularly in some key areas. Health care providers had proved to be reluctant to share their power for decision-making and for the implementation of health care services with those for whom the service was intended. This had included recognising that the patient and informal carers needed to be at the least, co-responsible for their own health and health care (Jacobs, Hagenaars and van der Veer; 2015). Another issue adversely affecting implementation of change had been the need for healthcare providers not only to provide care, but to invest in sustainable co-operative relationships within the health care system, changing the relationships with both patients and carers. However, some of the professionals appeared to have a rooted reluctance to the involvement of patients and informal carers in care planning (Cree 2015). In consequence any services changed had retained the current professional/patient boundaries, which limitedchanges moving in the direction needed for WMO. As a result over a decade since its launch, the coordination between the various organisaions involved, the Wmo (municipalities) the Long-term Care Act (Zorgkantoren) and

Nursing (Health Insurance Act) are still in their infancy. Consequently, there has been too little movement and there was no evidence of a 'drive' to change (Jacobs, Hagenaars and van der Veer; 2015). In addition for this study it was a concern that some of the key steps in Kotter’s (1995) were not a complete fit with the study. There certainly was aneed to develop a sens of urgency, but issues had arisen about the lack of practical guidance in the Wmo, which in effect had a guiding coalition, in the form of the government. Also the vision, strategy and cgange strategy had already been set out by the Wmo, over a decade ago, and it was thought that it would be difficult to encourage professionals to see these as new and to ‘buy’ into a process that had not been successful when treated as a continuous process, and that had left both professionals and patients wondering how to proceed. The outcome had been that few appropriate changes had emerged leaving progress into implementing the Wmo far behind what had been planned.

Although the step by step model had been identified as appropriate, it was seen as important not just to re-brand of use an approach that had already been tried and proved problematic, in consequence other models using a formalsed set of processes were sought. ADKAR (see below) was identified as a practical model for change for government, business and communities (Hiatt; 2006) This model has five steps from which the acronym was developed. It lists the necessary building blocks for change, they are described as the basic requirements for change and cannot be skipped or re-ordered if change is to be successfully implemented and sustained (Hiatt, 2006). Hiatt (2006) argues that this model allows change activities to be linked to measurable standards, an essential element for moving through change.

ADKAR

A Awareness of the need for change
D Desire to support and participate in the change
K Knowledge of how to change
A Ability to implement change
R Reinforcement to sustain the change

6.8 ADKAR model

This model is clear, succinct and has clear guidance for each step necessary, it has been successfully used with business (Boca 2013), to improve safety behavour and support the implementation of safety programmes (Al-Qahtani 2010), and in health care with nurses to assess their readiness for change (Kachian, Elyasi, Haghani 2018). However, as conceptual framework and model needed was for the implementation of change in the community it was felt that direct mention of of key participants such as families, patients and professionals was needed. The challenge for this project was that while each model offered a partial answer to the need for a wider application of the family unit model, each on its own did not address all key issues. Further study did not idemtify any models that seemed as appropiate, in consequence it was decided that the best way forward was to develop an amalgamation of both Kotter (1995) and Haitt (2006). The final model developed from combining the two models contained 8 steps specifically desgned to address key concerns. To clarity how this model works in practice, an overview of each step has been given below, with examples from this study where appropriate.

Step 1: The identifiation of need, the sense of urgency or the 'now-or-never-feeling'

The process of change requires first of all a shared sense of urgency. It must be clear to everyone that a change is necessary to implement a new vision. That fact alone may not be enough to convince people of the need for change. It must also be clear that the change must be started now, that it is a matter of now or never. It is therefore necessary to communicate clearly and clearly what the new vision is and what the associated methods and what will happen if the change does not take place. The emphasis has to be on monitoring and formative and summative evaluation of services. Services need checking for accessibility, appropriateness and acceptability of services (formative evaluation. As well as the efficiency, effectiveness and the extent to which they meet planned service goals (summative evaluation) (Patton 2015).

The study findings provide clear examples of the use of research activities to identify service needs. Other data sets that can be used include hosptial and community health returns, public health end epidemiological statistics. Government reports and evaluations as well as reports from patient groups can also be used.

Step 2: The development of a strategy

The change process has to be set in motion. This requires a team of people who have to create and maintain support, plan and monitor progress and motivate and inspire people. In addition, this group of leaders must take into account the diverse interests of various stakeholders in the hospital - such as employees, patients, the physicians team, the board and various other parties involved - and turn these interests into one common goal. A steering to provide support, expertise, strength, trust and leadership combined with a clear understandiong of health care needs for carers and families of patients.

A 'change vision' must be formulated, which is clear, desirable and feasible. It must be clearly communicated, illustrating what the benefits are when the goal is reached. A vision for all stakeholders must be viewed in the long term, since this is essential for the support of the change. Plans may be ambitious, but must be in line with the government strategies. The message must be recognizable and simple, easy to share, interactive and invite to action. There must be room for dialogue with each target group, so that the vision is not forced on and every stakeholder is involved in contributing to the translation of the vision into concrete impact. In this phase, all relevant actions, decisions and developments must be communicated as much as possible to all stakeholders.

A team of experts to lead strategy development needs to be set up as a steering group. It needs to be multi-professional, with the chair of the group identified and each member given clear terms of reference, identifying their individual and corporate roles. The legal issues must be paramenount, and the financial resources accountability clear and transparent. In this study an independent chairperson was asked to check that he following parties were represented: The dominant health insurance company, joint municipalities, healthcare providers, housing corporations and joint health organisations (GGD). The challenge for this group is to reconcile all the competing and diverse issues that need to be considered when policy planning. It is essential that policy plans encompass all strategic levels from individual care right through to the highest relevant level for the change planned. The starting point needs to be current policy, identifying strengths and gaps and comparing it with the wanted outputs. The process needs facilitation.

Step 3: Facilitation

Once a steering group has been formed, it must identify the common goals that can be jointly pursued. The role of the facilitor is to motivate participants within all government and healthcare institutions involved. They need to want to follow the vision, but throughout there needs to be room for flexibility. The role of facilitation and coordination here, is to ensure that the the vision is clear, understood and the actions needed to bring it about feasible. To change the course of an organization, everyone in the organization need to knows, understand and accept the new and changed vision. The facilitator needs to help all involved 'own' the vision, only then can it start to come alive with participants wanting and working to see it delivered

Step 4: Recruitment and dissmenination

It is crucial that the appropriate personnel are recruited to aupport the steering group's activities They form a key role, they need to work to together following guidance from the steering group. It is essential that this group fully understand and endorce the planned change process. They must subscribe to the vision, adopt the new working methods and have influence within the arena in which they operate. They are the ambassadors of the vision and the change process, they will be activiely engaged in all stages of the planned changes and willlead dissemination across organisations. Care must to taken to monitor their progress with any delays, disputes or disruptions addressed as soon as they arise. Without ongoing monitoring and evaluation the whoie process could be delayed. Actions and activities that The change process can deal with a positive critical attitude but cannot afford to allow disruptions and / or delays that add nothing to the change itself.

Communication to and between all involved in designing and developing strategies for change and key stakeholders, must be carefully planned and organisaed. In doing so, stakeholders must be given time to familiarize themselves with the change vision, and access to information and discussion. Next, be communication channels must be set up for conveying the message to, and wihin, each target group. It is essential to check that all communications are agreed and aligned with the message given to the various stakeholders. For the staffing, the independent chairman nominates and appoints persons who can represent the institution or organization concerned.

Step 5: Education of health care and socal workers

In this fifth phase, the goals of the change process must be linked to the individual objectives and job descriptions of employees. It is essenital to invest in the development of employees and managers, without their understanding and support, new initiatives are difficult if not impossible to implement or sustain. Therefore there also need to be tailor made training and education programmes so that all involved are clear regarding the vision, and planned changes in roles and activities needed, have the opportunities to gain the skill, expertise and competence needed. Planners need to recognise that every organisation will inevitably have to deal with organizational and human challenges and barriers as they consider how to work to implement changes in the organization's structure.

Education has to be designed to offer strategies to help address organisational barriers and thresholds, and to address the issues linked to human factors, which often form a much larger barrier. Reasons for opposition are often diverse in nature, and can come from a range of sources, education and training initiatives need to be developed recognising they can include skepticism, conflicting interests at either corporate or individual level, personal resistance to change, and fear of change.

In this study, a clear example of this was the development of education and traiing for the health professionals: The 'Leergang Informele Zorg' , is a training programme for health care and social workers. It was developed for two reasons, firstly, the feedback from participants (equates to step 1) the interviews had revealed the extent of the difficulties the informal carers reported whenever they tried to access help and support. Secondly, meetings with professionlas had led to them asking for imformation and guidance as they tried to address the problems identified in practice and move towards community based service provision. As major changes were neded a train the trainers approach, as this would cascade the reuied expertise more quickly, than short training courses just for the professionals.

Currently the first cycle has been completed and training programmes are now being developed for other groups of professionals such as general practitioners. However, sadly, training has been delayed by the Covid-19 pandemic, although it is hoped to restart later this year

Step 6: Education of health care and social work students

For the new vision, policies and practice to be sustained, all those entering the professions, as well as those in practice must understand the new approach. In consequence, education and training programmes must be developed that describe, why the changes were needed, and how and why they work. As the profesional curriculum has to be changed, nurse, and health and socialwork educators have to be involved as it is their responsibility, to make the necessary adaptations to the curriculum for the future professionals.

All adaptations need to be integrated into all nursing and allied health and social care professional education and training courses. The move to collaboration between professionals and informal carers, with more power going to the informal carer is a change from traditional practice, and it is essential that students understand why the changes are being made. They also need to understand the reasons for moving to a fmaily unit diagnosis, rather than focusing only on the patient.

As an example: the findings from the study, including the new roads, and the proposed changes in practice were shared with key educators. Working with them, additions for the education and the training programmes at the local university were adapted from the professional train the trainer programme, for initial education and training. This approach was taken as it provided continuity between education and practice. Curently it is a specific module which has been added to the curicula for health care and social workers, taught at the university.

Step 7: Family and patient impact

This, the penultimate step An improvement in the support of informal caregivers by a home care provider. From the latest studies on informal care, was clear that the support of informal caregivers must change and innovation had not followed the WMO recommendations. The policy is no longer aimed at offering support options such as a listening ear, emotional support, information and advice, practical support such as the deployment of care volunteers and various forms of respite care. It is essential that clear information be developed to enable them to be aware of their changing position, and are encouraged to seek for informal support, clearly indicating the form of support(s) that would best help them at that moment**.**

The support of individual carers must be improved by setting better and clearer requirements for this support at regional level. It must in any case answer the need for and availability of information, the possibilities of tailormade support and the accessibility at local level. Each resident should be able to get a complete list of the local addresses and regional organizations that can support carers. This can be done by developing a folder, a book, a website online or through an informative conversation with a social worker if needed.

Examples: Following this study, in addition to the information developed in each new road. An inensive training course has been developed for informal carers, patients and other family members, Called : 'The art of caring and letting go'. Informal caregivers who have followed this intensive training indicate that they are less burdened and can be active for longer and healthier as carers! There are now hundreds of Twente caregivers who have followed this training.

Step 8: audit and evaluation

The process is not static but dynamic. As the final of the 8 steps, audit and evaluation are the final processes that need to take place regarding the formulated and achieved goals. Change processes takes years and monitoring and evaluation are needed at regular intervals to make sure that the processes inherent in the steps have all taken place. Thatchanges have been sustained, and that asmore changes are needed to enable the care to remain current there are strategies in place to facilitate these additional changes.

Although by this stage the change is active and the first successes are in, the final phase also remains important. Here the change has to be anchored and sustained within each organization. Permanent change is a process has to be assessed retrospectively, over two to three years on average. The steering group remains responsible for embedding this change throughout the process and must check for cultural changes within the policies of each organisation. In the final phase the long-term vision must be re-assessed and checks made that it has been adopted. It is essential to embed the long-term vision at management level and check that short-term interests have not been prioritised. Successes must be shared and communicated, to encourage coninuing commitment. As success becomes visible, more groups wish to participate. In addition to corproate monitoring, individual assessment must also take place to identify where additional support is needed, and where positive outcomes should be rewarded. It has to be accepted that for some the changes will remain difficult, and, where this is the case they should be supported to find a role and funxtion that they are comfortable with, which it has to be accepted may be in another organisation.

Example: A complete overview of evaluation questions and audits have been developed by participants in order to review all changes. They are specific to each organisation, and ina ddition to assessing performace to date, they propose necessary changes, with organisations then repeating the 8 steps again. All of these audit and evaluation programmes are based on national standard standards

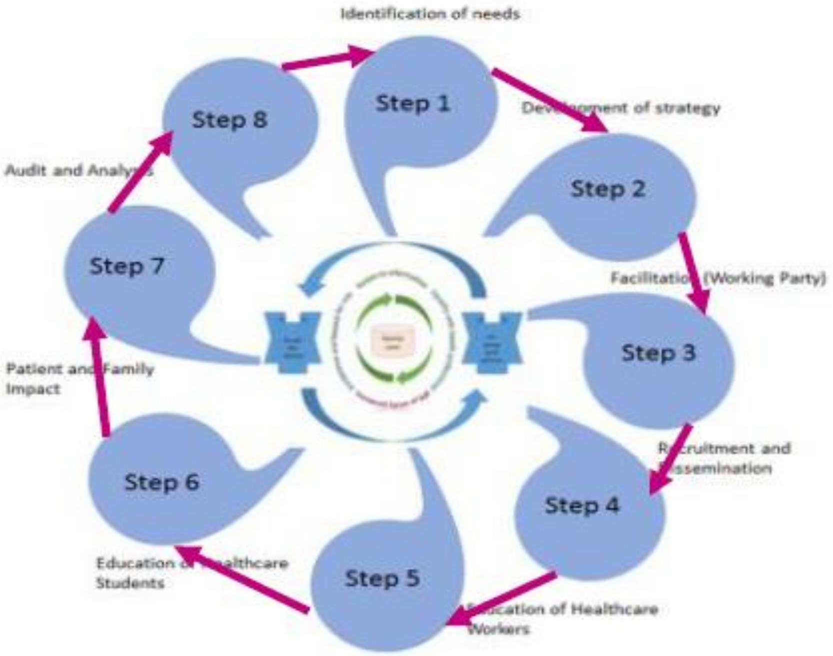
6.7: Presenting the steps

The 8 steps needed to be presented in a format that was easily accessible by both service users and service providers. Whiles lists and descriptions as given by Kotter (1995) and Hiatt (2006), do delineate the steps to be taken, they are to some extent abstract. Hence they do not immediately give the reader a clear indication of how the steps relate, and inter-relate, or the processes inherent within each one. As a result, how the framework and model work may not be readily evident to all readers, or understand that the conceptual framework is the overall structure, which applies locally, regionally and nationally, while the model is the family unit model of empowerment.

In addition, it was seen as important to emphasise that while the project approach was being used to facilitate the major changes needed, the nature of health care is such that when the final step is reach, it is not static, with one iteration completing all the changes needed. Instead, the dynamic nature of service provision means that as with action research, the cycle has to being again. The decision was therefore made to present the steps as a circle that the providers and users continually move round as social, economic and individual health needs change.

6.9 Presenting the 8 steps

However, while this demonstrated the structure and the cyclical nature of service policy planning and provision that needed to be carried out. It did not demonstate how the family unit fitted within it. It needed to be modified to include the individual model of empowerment, with the family unit central to all care, and the final diagramatic representation is given below



6.10 8 Step model with Completed Model for Empowerment for the family unit

With these integrated models that have been converted from individual to family unit level and fitting into a complete program of change management, an important condition for realization has been made transparent and workable, concrete. They fit into the nationally formulated framework (policy) and can be applied at a regional level. Because regional parties such as community health services, training institutes and health insurers do not operate on a local - but regional or even national scale, this entire process of change needs to take place on a regional scale, fitting in the national policy. It will be an enormous operation that requires much effort from many participating parties but ultimately creates a new and improved situation for the informal carers of people with dementia.

Chapter 7: Many New Roads

7.1: Introduction

The previous chapters have shown how, as the study progressed additional activities were initiated in parallel to the study, as response to identified need. The essence of the study continued as the core on which all activities were based, but the outputs developed and changed as the data set grew. This is an advantage of Charmaz' (2006) approach to grounded theory being used in health care research, with the richness of data gathered, arising from the ability to probe and explore the lived experiences with participants. The simultaneous data collection and analysis, guides the research process with the iterative processes used maintaining transparency, and demonstrating how the research questions become refined to remain the focus, as the study moves towards saturation (Charmaz 2012).

In this study, the nature of the sampling frame was such that all those interviewed had some shared experiences and concerns, as well as individual perspectives and descriptions of the disease trajectory their loved one was following. Their willingness to share their lived experiences, and to raise hitherto unrecognised issues, added to, and enhanced the quality of the data collected. The researcher is part of the study and the relationship between researcher and participant can impact positively on the sharing of lived experiences and the depth of information gained (Int Journal of Qualitative Studies on Health and Well Being 11, June 2016). This research, was led by a mental health care professional, known and trusted well before the study began, and interviewees openly stated that they were happy to share and to ask advice as necessary. The completed rich data sets contained such a wealth of information that it was possible for coding to lead to emergent themes. These, fitted into three main categories (emotional and personal support, technical support and wishes and needs), but greater insight was gained by further subdivisions based on age, role and setting. Using these refined themes, it was evident that the planned framework and model for the family unit needed to be much more complex than had been originally envisaged, with no one approach resolving all the concerns raised.

Accompanying the iterative research processes, as new items were incorporated into future interviews, the ethical principle of health care professionals responding appropriately to clients or patients was a key factor. Each new issue raised by carers was careful studied to assess its impact on care provision, at first regarded as a 'spin-offs', which could run parallel to the main study, as the research progressed, it very quickly became apparent that they were integral to the study as a whole. The whole ethos of this study was shared participation and therefore a strategy to be developed to present the complex and comprehensive developments in a format that could be easily accessed by all who read the documentation. As each one was established, it seemed to gain a life of its own, and to develop exponentially, so for clarity, the four main areas of activity have been separately described, although they arose concurrently, with each one supporting and adding to the others, although they were also divergent., and followed their own path. Using the interviewee's concept that they were on a journey, each of these has been described as 'a new road' which would contribute to the framework and model as a whole. To show show this worked in practice 18 key activities and projects have been selected and presented below. These are:

1 The road of support for young carers

- The project Buddys for young carers
- The National TV series
- The buddy project
- Royal recognition
- Publicity and a leading position
- Appeltjes van Oranje: a prestigious prize

2 The road of support and emowering for adult carers

- Rethinking the possibilitys: Hubers positive health
- The development of a training for adult carers: empowering
- The carers café
- A toolkit for carers
- Respite care possibilitys
- Becoming respected partners in care
- A video of the carers journey

3 The road of training the professionals

- Developing a training
- Writing a manual
- Development of an online tool
- Orientation with ICT providers

4 The fourth road, empowering the community

- Veurmekaar, developing a movement in society

Each one of these activities and projects is distinct with and has its own aims and outcomes, processes, and procedures. All have developed what on reflections seems to be a ‘life of its own’. Each one is continuing to grow and expand, and all are gradually moving towards functioning independently. They all fit in the new way of supporting carers, professionals and the community.

1 supporting the young carers

As the data collection section indicates, the first new activity identified was for young people, who, while part of the family unit and needing to be treated as such, also have their own very specific needs. The study was origianlly designed to support adult carers, their descriptions and explanations of the issues that concerned them, and the realisation of the type of social and emotional support being asked for by adult carers could not be ignored. Thus, the response to this group road formed the basis of the second road. However, as the programmes for this group developed, it was evident that for these to be implemented and sustained beyond the lifetime of this project, health care professionals needed to be aware of their spoken needs, and a training programme was developed for them. This formed the basis of the third road. With these three ‘roads’ functioning it was recognised that while the strategies would help individuals, there was a need for a collective response to support the community as a whole, and this them led to the development of the fourth road.

The four roads contain a total of 21 new initiatives, all were designed for, and implemented in Twente, but it was immediately apparent that my organisation SIZ Twente and I could not do all of these alone. With one exception: in the development of the online life album SIZ Twente was the initiator, but it was and is the lead organisaiton in all activities. The realisation of the need for help, brought with it the recognition that policies needed to change if new services and approaches were to be made available on a wider scale, and therefore a way had to be found to develop the strategies and policies to support inter-professional, trans-disciplinary and inter-institutional working. Thus, the roads all had to be conbined to develop a transformative policy framework and model for practice. To demonstrate how this was done, this chapter presents the four roads, and then chapter 7 demonstrates how these were used to develop the policy framework.

Reflections

All the activities that were initiated, needed to be merged together into a coherent care package for better and extended ways to support carers. The nurse was happy

because of the development of direct access services that carers need, based on expressed need. .

The manager was pleased by the start of increased systems for support that were developing and the beginning of the integration of different services from different organisation. However, was desperate to find ways to sustain the many different developments all at the same time. Leadership, organisation, and cohesive management were essential. It was a relief as organisations asked for information and ways to help share access to services

The researcher realised that yet again he would have to put practice before the research, and to wait ……. All these different developments needed attention … however, once it was clear that they were integral elements of the study each one could be followed and utilised to support the completion of the study itself……... and the research could move on, albeit differently to how it been anticipated.

7.2: The first new road: an essential chain of events…the project for young carers

As indicated earlier in the study the email from the young girl whose mother was an interviewee had a major impact on me, and on the study as a whole as it was followed up, and turned out to be the starting point of a chain of events that no one could have envisaged. There was no doubt about the need to contact the girl by email to ask how she was and to set up any extra support she was willing to accept, both immediately and in the longer-term future. The first step in helping to support this girl and to explore the issues around young people was to search out and establish a meeting with colleagues who were working with young carers. Although a relatively small group, nevertheless they were the only organisation to offer direct support to young carers. Their main referrals were from young people supporting family members who needed physical care and aids, but they were keen to support all young people regardless of the reason for them become a carer, and whether or not they were the main carer. They too, were distressed by the email, agreeing that it illustrated very clearly the crucial message the problems that can arise when children are excluded from information and in consequence do not know what is happening, what is expected of them or how to help the household or family. They argued need to feel that they are valued members of the household and have their own place in the home life and care being delivered. All roles have to be recognised and supported if the family unit is to survive and the difficulties of caring are to be properly addressed. However, the meeting also revealed that while there were the possibilities to support this girl, in their view, this was the tip of the iceberg, with countless others living in families or households where family members were carers. They argued that all young people need to know that help is available, and how to access it. They were delighted that I wanted to extend this type of service into the Eastern Netherlands,   and offered to take me to a young carers group to enable me to ask them directly for their perspectives on the problems they faced, and the nature of the support they believe they need.

It was important that the young girl was consulted, so with the approval of the group, and the young girl, I joined a meeting and asked what would really support them in a situation such as the one the in which the young girl had found herself. It was important to discuss the deeper issues that had led to her reaching out to me. How could we resolve this, and find ways to help young people without betraying their confidences and possibly upsetting the family dynamics further. The answer from the group confirmed what the email had indicated, when excluded from family discussions and issues about a loved member of the family they felt lonely, rejected and struggled to cope with being the *'outsider'* inside the family. They accepted that their parent's aim of protecting them was genuine, but argued that 'it *isn't right… I'm part of the family…'* so actually it did the opposite, at the same time as it sheltered them; it excluded them, they felt *shut out'* stopping them from being full members of the family, and sharing all the ups and downs. They recognised the challenge their parents faced, and suggested that maybe someone (young person) of their own age, who had experienced similar feelings, could act as a bridge, between young people and their parents. They repeatedly stated that they had found it immensely helpful to talk to others of their own age, they wanted and needed a '*buddy'* of their own age, with whom they could share their concerns and seek for ways forward. The need was ongoing, they kept attending meetings, tried to bring in and support newcomers and wanted all young people to have help.

The group visited, had a high staff to young person ration, and were adamant that currently, while they really wanted to help, they could not cope with a sudden and major influx of young people without additional resources. However, they were also aware that the problem of appropriate support was real and urgent, hence their willingness to meet with me. This study had enabled one young girl, to seek help, and had started a new chain of events, but the question remained as to how many others were in the community who also needed help and support. After careful reflection and discussions with the young carers group, the decision was clear, there needed to be a new project along the same lines, developed from within my study, which would be called: 'The Experienced Buddy'. For this to work, the next step was to find young people, and young adults who had shared similar experiences in their past, bringing them together with young carers who needed support. The aim of the project would be to enable them to spend time together, to do things together, to talk about their shared experiences and discuss '*what worked and what didn''t*, as they tried to cope with each new day. This experienced buddy would be outside the formal health services and as with the group visited would take on the role of befriender and guide.

It was important that the project was planned with the young people, using the perspectives of young people, not what they described as the misconception that they always have to deal with extra tasks in or around the household. They argued that adults think such activities are not suitable, pushing them into adult roles and removing their childhood. However, as they pointed out, what tends to be forgotten is that the very nature of having become a young carer, or watching your family struggle results in moving away from what is usually seen as a 'normal' childhood. Using the format of 'experienced buddies' as guides the project was started with minimal funds with professionals working as volunteers. The project was an immediate success, resulting in local and ultimately national interest with the Secretary of State of the Ministry of Health, wellbeing and sport asking to visit the group.

When he attended, the young carers two young carers offered to present and talk about their situations. This was an important turning point, as often happens when ministers attend meetings, many other professionals and families also attended. The young carers were repeatedly asked about housework, shopping, cooking and cleaning the house. Their responses silenced the audience and permanently set the direction that the project would take, they were adamant that for them it was part of their life and they willingly did it:

> *'It is not the work that makes my life difficult … it is not the care activity itself … but the worrying about [my loved one] … that makes me tired … I always think about the situation at home … it never leaves me ….that's the real burden.'*

They made it plain that their needs, just as identified for the adult carers included age appropriate emotional support, with the worst thing being 'always worrying'.

7.3: The Response The National TV series

Immediately following this public presentation, there was a request for a young carer of a loved one with dementia, to help with a national television programme, because of the buddy project. They had recognised an increasing need of activities for young people affected by the impact of dementia on a loved one. However, while I was adamant that we would support whomever they linked with, there would be no isolated and/or unsupported interviews or activities. As the additional activities within my study had given me unique insights, this led to me working with a national TV network to make a television documentary based on a case study from a real-life situation. I sought for and gained ethics and parental approval, to include a young boy who was a member of our support programme for young carers. He had settled well, wanted to help others understand and cope with their own situations, and was thrilled with the opportunity of creating something positive from his difficult experiences. He saw himself moving from being one of the family carers, struggling to cope with caring for his father with dementia, to a boy who could help and guide his peers. The whole of the family unit was involved in caring, and supported each other, but this did not negate the stress and distress they shared from watching the slow disappearance of a whole person, with only a small part of the man they knew and loved left. The safest way to include him was to make his story part of a series of television programmes about young carers covering a range of diseases and illnesses, impacting on the lives of young people moving them from children to carers, as they moved through adolescence to adult life. This series was very important, it led to young dementia carers in the Netherlands, being nationally recognised as carers for the first time. Called 'bikkels', a Dutch term meaning tough (young) people, it meant tough in many ways, emotionally and physically, this boy was only 13 and his father with dementia was not yet 50 years old. In contrast to all his friends lived who lived what he saw as 'normal' family life with their parents, his life was very different. As a portrait, the programme was both shocking and poignant. It was very impressive, but sad, with reality graphically portrayed. It used real life examples, he, his mother and sister gave his father a watch for Father's Day. A few minutes later the boy asked his father what he thought about his Father's Day present. First, he said that he hadn't been given anything, then that he couldn't remember being given anything. The boy's face was haunting as he struggled to find words and then quietly said 'look what's on your wrist'.

7.1 Picture TV series: the young carers

His father looked, said: 'oh yeah', but could say nothing about the watch and clearly, within a couple of minutes he had forgotten again. For the boy and his family this hurt, they had spent so much time and effort in finding a present they thought his father (as he remembered him) would like. They were desolate, it reinforced the reality that his ‘father’ was gone, there was a physical person to care for and love, but it was a shell. All he and his family saw, was an ever increasing loss of memory and lack of recognition. The boy was left to wonder what in their relationship would be lost next, and when would the day dawn when his father did not even know his name.

Following the broadcast, I checked how the young boy felt, being able to share his experiences had proved to be very positive, but he was concerned that now the television programme was over he wouldn’t see the team again and would be back on his own. I was quick to assure him that the support he was already receiving from me would continue, but for me this was only an interim arrangement. I was a much older adult, he needed more friends and support from within his own age group and that I could not do. There was only one solution that I thought might work, expansion of the project ‘experienced buddy’ to a long term arrangement. Instead of some individual support and group activities, the individual buddy link would become a permanent feature, this entailed going back to the young people already linked in and asking what they thought. I then worked with them and colleagues to develop a training programme to help them colleagues gain the skills to support young people over time, and to select and train some young people to be formal ‘buddy’s. These youngsters were then linked to those in need of support.

The initial group were highly motivated, and the training had an additional benefit in that those who attended it reported not only being able to support others, but better able to cope with the challenges in their own lives. As a result, the training was refined and an established element of voluntary support for young carers. Every effort has been made to check that these young people, where possible can follow the normal patterns of their peers, meeting together in groups and developing things they want to do together. For this to be sustained, they need to have as much autonomy as possible, so, a youth group was established that the young people can utilise and run themselves with professional support, and where necessary guidance. As young people are identified they are invited to the group, to discuss and share their experiences with someone who has been and often still is in a similar position and they can then support each other. They are encouraged to identify for themselves which members of the group they feel comfortable with and from this with great care, the young people and professionals work together to ‘match’ the young person a buddy to facilitate ongoing support. For this to be sustained we had to have more finance. We had to look for grants we could apply for, and I undertook to write bids with them and submit them to suitable organisations. We wrote a short summary of what the young people believed the experienced buddy project was, and put it together with a picture:

ERVARINGSMAATJES

Experienced young buddies

Sharing your worries can reduce worries: you know why

Experience buddies is a project in which young volunteers and interns who have grown up with caring needed in the family, to provide support to these young informal caregivers. Often, nearly all the attention and care goes to the sick or affected family member, this can be difficult for all other family members as it leaves them unsupported. An experienced buddy knows better than anyone what that feels like, especially for the young child or adolescent whose life is now restricted. They offer a listening ear, support in practical matters and are there to try to put some fun back into family life. He or she also gains insight into the personal wishes and needs of the young informal caregivers, and can help them access specific care and support.

7.2 leavelet project young carers

National care innovation prize

This project was now inextricably linked into the slowly emerging conceptual framework of support for the living family unit, but even if it had not been, ethically I could not walk away from such strongly identified need. A solution had to be found, and I found a call for proposals from a national scheme Nationale Zorgvernieuwingsprijs (National Care innovation Award). This scheme was designed for groups wanting to use innovative ideas and approaches to offer better care, and through that increase well-being in the Netherlands. It is prestigious award overseen by national organisations including the Orange Funds whose patrons are the King and Queen of the Netherlands (The House of Orange), and a proposal was written and submitted. We thought that even if we did not win, all applications are publicised and that could gain us more interest and ultimately finance. If we did win, then the funding would help us respond to the ever increasing numbers of young people getting in touch seeking support and guidance.

To the excitement of the young people, the project passed all the selection rounds and was part of the final 10 projects, at the end of 2014. Within the buddy group there was unanimous belief that the project would win, trying to explain and convince then that selection into the final group of projects did not mean that winning was a ‘fait accompli’ was not easy. Waiting was difficult for everyone as without money from an outside source the project was beginning to stall, and we could not take on all those asking for support. However, the young people and the professional support team were right, the project gained national recognition from the publication of the short list (which on its own would have helped us find some more funding) and then in a dream come true, it won. The project was given €150,000 to use for the benefit of young carers, and has now been successfully extended across the whole region, and is now beginning to establish itself as a national movement for young people, led by the young people themselves. It fills a gap not identified before this bigger study, but increasingly recognised as essential if young carers are to have the best possible support as they travel with their loved one, along the progressive journey of increasing dementia in a loved one.

It is a sobering thought that, but for this study, where a young girl listened and acted, there would still be no formalised support for this special group. It was not a planned activity and it took courage, firstly for the young people to accept and trust an adult from the professional world that had up until then ignored their needs. Secondly, for me to admit that the initial plans for the conceptual framework were incomplete, they had not encompassed the needs of young carers, and then for me to work within the study to find a solution they could accept. It was a conscious choice to put the young carers into the study and to work around them. Looking back, although it delayed the completion of the main study it was true to the aim for a family diagnosis and support for all members of living unit. It is hoped that it can also be used in situations where carers provide someone with a disability other than dementia, because the position of young carers of loved ones with dementia also applies to all young carers, regardless of the type of disability of their loved one. After all in paediatrics, when a child is all, it is accepted that parents are involved in the care and treatment for their child. They are placed in the lead with everything discussed with them. The question remains of why we hadn’t taken that as a normal procedure in situations in the converse situation where young people are involved in the care of their family member, instead of closing them out, causing stress and distress.

7.4: Royal recognition: The visit of our King

Following the award, as the project grew, national interest, stimulated by the previous activities also grew. In 2015, King Willem Alexander, the patron of the Orange Funds decided to see for himself how the winners were progressing.

After a multitude of security checks, the working visit rather than a ceremonial one took place. There was no publicity prior to his visit, other than the mayor of the town being informed. Only a small number of colleagues working on the project were there, but most importantly, the young carers themselves were present, they did not know who was coming, just there was a meeting and their help was needed. They were stunned and excited when told just beforehand, it was beyond their imagination, they saw themselves as just young people struggling to cope with their loved one with dementia.

King Willem Alexander chose to talk to the young carers and their buddy's. He was very well informed about the project and had special questions for them.

7.3 Photo: sharing the same experience

7.4 Photo: talking with the King

He asked a boy of about ten years old whose father had Parkinson's about his situation at home. Health professionals are well aware that this often can lead to depressions and dementia, but for a boy of 10, the dementia had been unforeseen and difficult to understand. They did have good times when his father was well enough to football in the scootmobile, but it was difficult at home. His father found it hard to stay awake, so he took him cups of tea to help him wake up, but he was sad, because he couldn't bring his friends home after school, and often couldn't do what his friends did, saying quietly '*sometimes it is not nice at all'.* Perhaps one of the most moving aspects of the royal visit was The King's response as a real 'experienced buddy'. His own father, had suffered from Parkinson's disease and he chose to share this

> He said that he knew what the boy meant…. his father had also Parkinson's disease and him just like the boy… he couldn't do what he wanted to do with him... he couldn't 'play fight' with him when he was young … he couldn't join in…. for me too … it was not always nice at all.

The boy's reaction was immediate, he beamed, turned to us and said: '*The King and I have the same problem'.* He was very emotional about the King's willingness to speak to him as an equal who shared his challenges and not as the monarch to a child. By sharing his experiences it was as if the King gave him permission to want to be a 'normal' child, to want to play and make his own choices, while at the same time accepting the reality of the disease his father had. He had been given a very precious gift, that of knowing he was not alone, others had faced the same challenges, had hankered after what they could not have, but that this had not diminished their love for their parent. This was two individuals sharing their very similar experiences. They each recognised the other's problems and that brought them momentarily close to each other. Sharing an experience, sharing feelings needs trust and acceptance; it was moving to see them cross all barriers of age and position as the King reached out to help and support the child. The reaction of the boy both then and afterwards clearly illustrates that a problem shared is a problem halved

The King was also interested in what he described as 'the state of the art' in Informal Care for those with dementia in the Netherlands, and the progress the project had made since winning the award. His grandmother, the former Queen Juliana, had suffered from dementia so he was well aware of the challenges dementia brings. He queried whether people really wanted to know what was to come, one of the pillars of good support is offering the amount of information needed, but not forcing families to hear everything all at once. I shared the findings from the study interviews in which the majority of the carers would have liked more information at a much earlier stage, with carers of all ages reporting 'I *needed it* [information] *so badly right in the beginning'* with participant after participant stating '*If only I had known*…..' The challenge for the professional is working out what exactly is wanted at any given time.

After the visit by the King of the Netherlands, it was clear that we were on the right track. We had triggered interest with our new method developed for young carers. We could now support many more young people not only in our region but across the Netherlands.

The manager saw a chance to extend this method and develop more new strategies for supporting young people. This was the moment! He wanted to take the momentum.

The researcher realised that he had to wait again ……. This new road had to be developed further. Ignoring it and work on it after the study was finished was no option….

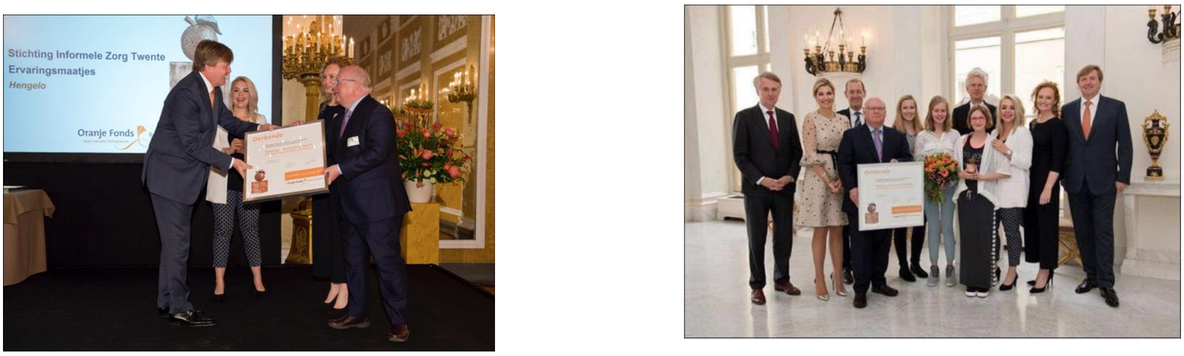
7.5: Publicity and a leading position

Inevitably, after this visit, there was a tsunami of publicity in the local and national newspapers and on the local television channels. To my amazement, this publicity cited me as 'the expert in the field of dementia and carers'. Every time there was a news item about dementia and or carers for people with dementia, I was and still am asked, to give my opinion in papers and on local and national television on issues linked to dementia in the Netherlands. I had to respond appropriately and not let it impact on the members of the project or, the living units I was working with, whatever their age or background. This was a challenge in itself, it would have been easy to allow the publicity to influence what the project was trying to achieve, but that would have defeated the objectives of the buddy programme. Repeatedly requests were made to take children and/or buddy's' to present at meeting but these were vehemently refused, the children and young people had to be protected at all costs. Nevertheless the project increased in speed like an avalanche as they progressed.

There were many organisations in the country who wanted to start the same project in their own region with help from myself and my organisation. Thus, Stichting Informele Zorg Twente became a leader in establishing informal care in the Netherlands and was, and still asked repeatedly to share their knowledge and expertise with carers for people with dementia and informal care as a whole. It was important that people and organisations did not listen to half the story and then try to implement initiatives without being aware of the full consequences both for professionals and for participants. Therefore, the decision was made to organise a national congress where information would be shared and questions could be answered.
While rewarding and helping the buddy project extend and grow, this also impacted on the main study, as it raised issues regarding support for all carers in living units. The problem was that the organisations linked to and enquiring about the project were now requesting training and support. There requests were increasing exponentially and it was evident that another strand had now to be considered; the training of professionals. So, what had started as a single aim to develop a conceptual framework and model to support carers had to adapt again to encompass this additional element if it was to be in a format that could be implemented and sustained.

7.6 Appeltjes van Oranje

The project Experience buddy's for young carers moved on and was developed further. It was nominated as one of the project for the Apples of Orange, 'Appeltjes van Oranje'. A very prestigious prize for important improvements in wellbeing in the Netherlands. From hundreds of submissions, there were 40 projects selected in a special national meeting for the best projects. Again, our project was one of this 40. During that session, the best ten of this 40 innovations were chosen and nominated for winning one of three Appeltjes van Oranje: the absolute top prize. Our program was chosen to be one of the ten best projects. These ten projects were invited to the Royal Palace in The Hague to be present at the announcement of the best of these 10 projects. About a week before the meeting in The Hague we got the news that our project was one of three winners of this prize. A great and unimaginable honour. We got this prize out of the hands of Majesty the King of the Netherlands.



7.5 Photos: receiving the prize, and the King and Queen with the project team

7.6 Photo: the winning prize: Appeltje van Oranje designed by Queen Mother Beatrix

Today, the project continues and grows, and is being used as a new national programmes with policies being developed to support wide scale implementation.

Activity 2: The second new road: empowerment for the (adult) carers

7.7: Rethinking the possibilities

As the individual interviews and the focus group interviews continued and were completed, I continued with the iterative processes and repeatedly read and reviewed all items. As I did so, gradually more and more insights began to emerge, as I sought to understand what they had been really saying and where are there shared links. As with English, in Dutch people often downplay their comments and the challenge for the healthcare worker and researcher is to look behind the words and in the light of the context try to gain awareness and understanding of what the leveed experience actually was and meant to the interviewees. It became increasingly clear that there was a consensus or 'central theme' that even if not explicitly mentioned was intrinsic in all the interviews. Interviewee after interviewee spoke about, or intimated that they were on a journey. However, unlike all their other journeys they typically stated that they had no clear direction, or were worried about how things would develop because they '*didn't know what was happening*' with typical comments being:

> *'I feel like I'm going to travel without knowing what I'm going to, and I do not know what to bring in my luggage.'*

After looking again and again at all the transcripts over many weeks, suddenly the central theme became clear to me, and I could see the way forward, 'the journey' was the heart of what I sought. Not a 'normal' journey, but one embarked on with trepidation, with anxiety, with a sense of dependence on others, and without being given a choice about going, or where to go. That was what I needed to use and build upon, I needed to find a way to change their journey, to take away the fear and anxiety, to help them to see where they were going and to make choices about what they take with them. Analysis of the data sets also explained what I had seen so often in practice, the apparent passivity of some carers, with an acceptance that they could do nothing, as one interviewee said *'what's the point …. Nothing… nothing changes'*. Whatever was developed had to be designed to address such negative perceptions of requests for help and support. It needed to include strategies to help them recognise where to go for help, whom to ask, and to gain the confidence to make changes for themselves. Only through this would they regain some control over their lives and find an appropriate way forward for themselves as carers, their loved ones and their families. There is evidence that informal/family carers take little time for themselves and that this compounds the problems of caring (Wie doet er wat; Social en cultureel planbureau 2015), and that it is often the inability of the informal carer to continue that leads to residential/ nursing home care (Een grote belasting, Drijgers 2010, Denkbeeld 22, 8-9) . The data sets clearly showed the guilt carers felt if they spent any time on themselves, and for considering when and if their loved one would need to go into care, with comments such as '*I feel so guilty … I promised him I would care for him*'. Their fear of not honouring their word ever present.

Looking in literature to see which strategies would be useful, Huber's (2011) concept of "positive health" seemed the most appropriate to consider for carers. It offers a concept of health in which functioning, resilience and self-rule are central, arguing that if individuals do not care for themselves long term they will not be able to care for their loved one. It has a crucial question for carers, individuals are encouraged to look at how they can keep themselves. The problem is that traditionally in the Netherlands, much of the support is offered in the form of information which the carer then has to interpret and consider which they can or should apply for. This does not fit with Huber's (2011) concepts, as while in theory they are informed about how to apply for help, the systems are convoluted and difficult to traverse. The focus and control remain with the local or national authorities, add to this the change to communities caring for themselves (without any additional resources) and the challenges faced by informal carers are evident. A search through all available guidance for carers, did find statements about the need to stay healthy, but little evidence of actual examples of activities that are practical, easy to apply and can be fitted around the responsibilities that accompany caring.

They described it as 'typical *official speak*', something they just ignored, with comments such as 'I *have no idea what they are on about'*. While accepting that interpretation of documents means something different for every carer, nevertheless, this is merely a blanket statement without guidance which does not offer a way forward, but on the contrary, caused considerable indignation among an already stressed, stretched and exhausted group. The emphasis of the support of caregivers should therefore be based on awareness, practical ways to cope and guidance on how to access and complete requests for support not just rhetoric. Strength comes from finding ways to help individuals and not just reiterating standard systems of support (Huber, van Vliet and Boers 2016). It was evident that tailor made support needed to be organized for the informal carers, with new support options designed for the current situation. Easy access to support systems is essential, with transparent processes that enabled the carers to see and understand decision about care and support.

The move away from the WHO (1948) definition focused on complete health and the absense of disease to a more dynamic one, where self plays an important role reflects the changes in scoeity since then. The improved medical care and increased life expectancy of humans are accompanied by an increase in chronic disease, where the emphasishas to be on living in the best way possible within each individuals own circumstances. (Huber et al, 2011;343(4163):235–7.moves towards a reformulation of where health can be summarised as: '

> *'As the ability to face the situation, to adapt and self-management in the face of social, physical and emotional challenges'. In 2011,* Huber et al., 2011

With this definition, the individual is central, with self-management and adaptation to circumstances crucial. There is an emphasis on what is possible, within an individual's whole environment. This approach is based on six main dimensions of health:

Main dimensions	**Aspects**
Body Functions	Medical Facts Medical observations Physical functioning Complaints and pain Energy
Mental functions and experience	Cognitive functioning Emotional condition Self-esteem and self-esteem Feeling control Self-management and Own direction
Spiritual and existential dimensions	Sentence Pursue goals or ideals Future perspective Acceptance
Quality of life ,	well-being Enjoy happiness To enjoy Experienced health Feeling good Happiness in living Balance
Social Participation	Social and Communication Skills Significant relationships Social contacts To be accepted Social awareness Meaningful work
Daily self-management	Basic general daily life activities Instrumental general daily life activities

7.7 Table Demensions of health

These dimensions were mentioned in the interview, an example of this is given below with the full details in appendix 3

Personal factors in caring

Motivation to care	**Feeling as carer**	**Lead dimensions**	**Aspects**
It feels good to care	I get enough satisfaction from caring	Spiritual and existential dimension	Meaningfulness Goals and ideals

		Mental functions and experience Quality of life Social participation	Self-esteem and self-respect Balance
It want to care as long as possible	I just don't care enough	Spiritual and existential dimension Quality of life	Ideals and goals Acceptance Wellbeing
This is the way it should be	I should do more: feel guilty	Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Acceptance Balance Meaningfulness Feeling well Veerkracht Resilience Self-respect

Table 7.8 dimensions mentioned in interviews

The concept of positive health fits well with the transition in care in the Netherlands, from the AWBZ to the Wmo, the Health Insurance Act (Zvw), the Participation Act and the Youth Act. It forms, as it were, a new landmark in the official government approach, with the concepts of self-management and self-direction now seen as central. Particularly in the field of public health, positive health can supplement protection against external risks, prevention of diseases and health risk behaviours and promotion of conventional healthy behaviour. It looks at a distinction between what people can do themselves and what the government can do to create a health-promoting environment.

The support for carers starts with recognition that the individuals is a family/informal carer is a carer. The challenge is that as the interviews revealed, many of those interviewed either had not, or did not not see themselves as carers. Changes in the family setting had evolved over time, there had been no one sudden point when the choseto adopt the role. Instead for the majority, it was a retrospective recognition by the family as a whole. Most of those interviewed would have liked to be formally recognised. The advantage of such a system is that it helps all concerned to accept the role that the carer has taken on, they (the carers) as then in a position to fight for support and added assistance for their loved one, themselves and their families. As it stands at present, many find it hard to convince health care professionals to listen to them, and to act with support and guidance:

> It was difficult.... the doctors wouldn't listen to me... they said it was not him [my husband] .. but me... but I knew ... if someone had given me something...anything saying I was a carer... it would have been easier to make them listen ....

7.8: Program to empower adult carers

The next step in the support process was to develop strategies that could be modified and adapted for each individual, to meet their needs. It is unrealistic to expect busy carers to have time to do as is currently expected and research all possible sites for themselves. There needed to be a package that professionals could use with carers to help them formulate their need of support, and then access services to guide, support and help. The new programme was called "the art of caring and letting go" and was developed with carers. This is an intensive programme for carers, which explores what caring for a loved one means to them, how it has affected their life and how they can use the available resources to identify and then ask for support. The diagram below shows the individual m surrounded by a circle whoch represent support, and the words literally translated mean ‘Informal Care and Letting Go’. A web page to support the programme has been developed and informal carers are are encouraged to access it , professionals can be asked to help complete any necessary forms

Mantelzorg
en loslaten

www.mantelzorgenloslaten.nl

Now that you see yourself as needing help, we need to find the best way of support for you as a carer, and you have to think about where you can go to get the support, and how quickly it can be developed for you

So ‘finding the right support’ flow takes a few steps:

1. Now you see yourself as carer for your loved one:
    a. *You can ask to be formally recognised, because the Ministry of VWS has made a policy that all carers can ask for an official document that recognizes them you, and the role you have as a carer*
    b. *You can find the document on the government site which says: Together we are stronger as informal carers , Ministerie van VWS 2020*

2. Next you need to sit and think what caring for your loved one means for you, what you have to do each day for your loved one and what support you think would make your role easier.
3. The third step is to show you where you can ask for the support, we have included a list of all the available support and a short description of where each one comes from
4. You need to look carefully and see if that is what you need, there are short forms that you can complete and send in to tell you more and to check that the support is right for you

5. We know that as your loved one’s illness continues you may decide you need to change the help you have, so you can return to the site as often as you need to and follow the steps over and over again.

7.9 : Logo and extract from the start of the programme

While this programme was being completed, the ongoing interviews included more and more rquests for somewhere that they could *‘meet with others.... who are carers..... it would help’.* They wanted to talk to others to see how they managed, to and to share their feelings with their peers. We had already held a few meetings where carers could come for a respite break of a few hours. It seemed that this was not enough, caers needed something that was there on a regular basis, and where they could meet with their ‘peer’ carers. They needed to be able to speak to others who are on or who have been on a similar journey, to share experiences and gain new ideas and activites that might help them cope. They need to be able to share their feelings, including the grief that comes as they lose the future they had planned with their loved one, but continue to care for the person they now live with. As one of the interviewees who was widowed explained

> *‘My family didn’t understand....I didn’t really cry when he died... he had left me long before he died... I looked after him... he was officially my husband... but wasn’t really there anymore....’*

7.9:The carers cafe

It was evident from the data sets, that this type of living grief was not unusual, and many had found it hard to explain to their families. For the family members and friends who grieved at the actual or physical death, it was hard to comprehend that the main carer had been watching their loved one slowly disappear, or in their words ‘*die inside’.* The carers need to talk to others who understand their feelings and will not make them feel guilty for feelings and reactions that do not fit with the social norms (Oudeampsen et al., 2007) To give them opportunities to meet that they could plan for, and that would be available week in week out, an activity had to be developed specifically for them, and it was seen as important to make it seem part of what they remembered as ‘normal life’. In the Netherlands cafés are meetng places for all age groups, most have both internal and external seating (with heaters for cold weather) and are open from early to late. Therefore if cafés could be set up specifically for the carers, they could resume the social activity of arranging to meet for a drink at a café. The cafés were designed to look like any other café found in every village, market town and city. Initially set up for a short period of time on specific days, it was seen essential that these could be accessed across the region, premises were identified, volunteers and professionals mobilised and then flyers were printed and circulated, adverting the first session. The poster below says ‘Monthly Meetings in multiple locations across the whole of Twente (the local region)

7.10 The poster announcing an informal care café in the area of Borne

Informal Carers Café on 17 february

Are you a carer, or do you know someonE who is?

If so, we are inviting you to join us at our new informal carers café. This will start on February 17 between 19:00 and 20:30 in the local restaurant, The Canal House. The café is a venue where you can come and meet others who are caring for family members, or close friends, or have recently been caring. We have set up the cafés, because we have been asked by family carers to find somewhere where you can all come together, not in a hospital or care environment, but in a recognised social setting

You may already know some of those who come, but there will be others there who want to meet you and to make new friends. You are very welcome to come just for a chat, or you can share as much or as little as you want. Everything is permitted, nothing is expected.

There will be volunteers, who also have experience with providing informal or family care at the café. They will have practical tips and can help you find ways to access support and services that can help you, so at every one you will find a family care consultant present.

From the start these cafes proved to be very popular with carers, and have become an established element of the support network for adult carers of all ages. At the rrequest of the carers, cafes are now help at different times of the day, as well as in the evening.

7.11 Photo: an example of a carers cafe

The cafes have continued to be held in local cafes and restaurants, as the picture above shows, each host venue keeps a banner which is put up to identify where the group are meeting. Feedback from the carers is very positive, one of the attributes that they report appreciating most, is that an onlooker will see only a group of friends chatting and drinking tea and coffee. They have the feeling of having resumed part of the life they used to lead, where necessary volunteers will go to sit with the person with dementia, hene at the cafe they can relax and enjoy the respite. Age and gender have proved to be no barrier, and members often work together to find a solution for a carer who is struggling. This peer support is crucial as the carers share experiences to find their own solutions to difficulties, so taking more control over their home situation, an important step in empowering carers and helping them take a leading role in care and care planning (Langer meedoen, Alzheimer Nederland 2018)

7.10:The toolkit for carers

As the cafes grew in popularity it became evident that member after member was reporting the same issues and concerns as had emerged in the interviews and focus groups. This re-enforcement of the findings from the study, could not be ignored, and in the final focus groups, the interviewees were asked to give more detail about the information they needed. They readily did so looking back to when things had started to beome difficult. For some this had been at the time of diagnosis, which as the interviews had shown was the first time their concerns had been recognised. However, almost unanimously they had not found that giving them the diagnosis had been accompanied by help or guidance

> *I did not know where to start …. I had no idea what to do…. or what was expected of me... or where I could possibly go …. Ask for help*

To address this problem discussions were held with the provincial care organisations, and it was agreed that we would develop an information pack, or toolkit specifically for caregivers, encompassing all the issues raised by interviewees and cafe attendance members, together with the information healthcare professionals thought was essential. Toolkit development started with a detailed search of all governmemt documentation on care for dementia patients, and available materials for supporting informal carers. Once the information was gathered and collated, a second search was then made of all webpages, voluntary societies and social media sites to check for any information missed. These searches took a considerable time and fully supported what the intervewees had told us

> *'it's so confusing.... I am so busy and I have to search... and search to find anything... anything at all... and then half the time I can't work out what it means for me ...'*

and

> *' I just don't know where to start... I'm not good with computers... half the time when I do get hold of something all it says is " you can find more information on the web page" ... so I'm back where I started ... with nothing... '*

The searches yeilded a wealth of information which then had to be reviewed for relevance, but as we worked our way through the mass of documents, just as interviewees had reported we too *' found it all very confusing'* moving repeatedly backwards and forwards between local, regional and national documentation. This was the first time that we had studied all documentation in such detail, studing national, provincial and local services, revealing to us for the first time, the full impact of the implementation of the WMO (2007) in 2015 on care provision and support services. Provinces and lcoal councils had been given flexibility in the extent to which they decided specific activities should be seen as being provided by the community itself. While in principle this appeared to be a suitable mechansism, with policy documents giving a clear rationale for the changes as it allows lcoal areas to ascertain what is appropriate for their own areas, seeing it in practice, it now appeared somewhat different. It seemed to us that each province, and local council had interpreted elements of provision very differently, meaing that those seeking information had to very carefully check what applied to them and what didn't. The result of this explained comments from interviewees that

> *' there are things I've seen ... that would help ... but they tell me I can't have them... why can't I... I don't understand'*

It had been difficult to explain the differences during data collection, seeing all the relevant documentation carefully categorised just confirmed for us the complicated and confusing situation support for carers was in. It seemed to us that the planned toolkit would need to be presented in sections clearly indicating universal (national) provision and including provincial services and support strategies separately. This would of course enable the informal carers to see the differences in provision of support, in terms of personnel and resources that interviewees had come across when talking to others from different areas.

Using all documents that seemed to offer relevant information from all care providers, I and my team, put together the first pack for carers, that had been developed wuth the service users for whom it intended. The final document was much more comprehensive that we thought possible. However, we thought that it would be too daunting, so following the principle of the journey we deivided it into separate booklets that matched with the main ’stations’ on the journey. The booklets were collated into a numbered series which could be given to the informal carers at recognised time along thr disease/ journey trajectory. Immediately the information appeared more manageable as each new booklet added to the content given in the previous one. I wanted this to be different, so information was prepared in two formats, a written booklet and a CD, and it was agreed each carer would be given both formats.

The final step was to devise a name that carers would find appropriate, and for that I reverted to the train journey and the book was called in Dutch: **Op Weg Wijzer** which literally translated to **On The Way But Wiser : a guide for carers of people with dementia.** BothCD and written text were designed to look attractive and weloming, using the colours of the supporting foundation, (see figure below)

Figure 7.12 The Toolkit

All booklets were completed using the same template, and the information in the first booklet in the series and accompanying CD (comprising the toolkit) has been listed below as an examplar. it included:

- A greeting from the Major, which included a statement regarding the importance of informal carers and thr high regard their role was held in
- Carefully worded Information about dementia as a phenomenon, giving explanations of the main causes of dementia.
- Description of where to find information on the internet or in books, this included carefully vetted web pages and will be revised each time booklets and CDs are printed /recorded.
- Information for carers, indication where in each area they could to find help and support
- Information about voluntary/ non-statutory care such the Alzheimer cafes in the local area
- Adresses and telephone numbers of appropriate professionals who could be contacted for help and/or advice

This pack was then made available to medical centres involved in diagnosing dementia, and to key care providers.

I thought these two intiatives were complete, but the data sets were again re-read, and the next area of concern that arose revealed that as with other activities the work to date was just the first step. The toolkit was going to have to change and adapt as the loved one progressed further along the disease trajectory. The issue that arose, was not about their own needs, but was linked to practical help being needed. This was different, the focus for the toolkit had so far been based around supporting the carer, suggesting help that would enable them to continue with the chosen role. Now it was evident that rather than seeking support for themselves, there were times when they needed practical interventions. For instance, carers reported that when their loved one developed '*problems'* that needed hospitalisation, the double changes in surroundings, firstly into hospital and secondly home again, caused confusion and agitation for their loved one. They had had no training or guidance in coping with agitiation and confusion. For some this was the first definitive sign that they were in wthe words of some *' losing the man I married... ' .* Although they knew the diagnosis, for many of the interviewees *I never thought I wouldn't be able to reach her... she didn't recognise me ... or the house ... or anything...'* . They were shocked, grieving both for the person who could no longer relate to them and for the *'state'* their loved one was in. They did not know how to ease the situation *'make him feel better ... to settle down'.* There is a wealth of research regarding the adverse effects of moving patients with dementia out of their familiar environments (Fleming et al, 2010) but it seemed that few carers had been advised, or could remember being given advice on how to help with re-establishing familiar patterns of living. As a result, information was added as a new section in the toolkit, one that could be given to carers to prepare them for their role when visiting their loved one in hospital, for within the rehabilitation process, for preparing for discharge and coping when the loved one returned home. This includes strategies that they can use to help prepare for change, as well as questions to ask about the outcomes of treatment or interventions. The sadness that they felt when even after appearing toovercome agitation and settle back into their home, carers found that

'She just doesn't understand... what has happened... why she feels different'

While information is helpful, and talking to others can also be useful, nothing had prepared the carers for the new situation they found themselves. They thought they had accepted the diagnosis and could cope, but such changes as they saw broght the reality home to them. They asked for practivalhelp, but it needed tempering with expert psychological support to enableg the family unit to work together to try to cope in a safe and supportive environment. It was evident that support needed to be ongoing, and while the tollkit had been modified appropriately, the information and possibiity of specialst mental hea;th support did not seem enough.

(See Appendix 5: A toolkit for caregivers of people with dementia in Hengelo)

7.11:Respite Care

The steps described above, may help, but they do not address the impact of coping without sleep, or the stress of having to continually watch and safeguard

> *'it's relentless… I can't leave him at all '''I am so afraid for him…'*

And

> *'I am just so tired... she gets confused at night... I am afraid she will fall... I try to take care ... day and night ... but I need to sleep ... but there's no one else...'*

The best way to help resolve their constant anxiety and fatigue seemed to be to find more ways to offer respite care. The need to provide this form of help, for informal/ family carers is well documented (De Boer en Van Campen 2009). However, when every family situation is different, so if the family unit is to be kept intact, a range of different, tailor-made respite options need to be developed, the challenge was that most of the centres offering respite care were happy to accept those with physical needs, the numbers able to accept those patients with dementia were much smaller. A way had to be found to provide more access to respite for this group, so I decided to approach the hospitals in the region and start discussions with the outpatient and rehabilitation centres. There too, staff were more used to dealing with physical challenges, nevertheless, they were willing to listen, and as the discussions progressed they agreed to pilot opening specialist areas within the clinics specifically for dementia patients to come to. Referred to as open informal/family care centres, they are attached to the outpatient clincis, but in a separate space. Separation is necessary, because the constant flow of people coming in and out of rooms where dementia patients are resting can be confusing and challenging for those with dementia (Giesen, Universiteit Twente, 2010). Staff with additional training in coping with dementia run these centres, the carers can relax in the same room, of bing their loved one and return for them some hours later. There are additional advantages to these centre, the individual with dementias becomes accustomed to attending the hosptial, so if they need admission, while they may not remember the centre clearly, it does seem that they are less agitated. This will be formally evaluated in the near future. Also, should they need any services such as physiotherapy, these are easily available.

While this gave some additional day time release, this was not enough for some carers to gain sufficient rest, particularly as their loved one progresses along the disease trajectory. There was an already available system, prior to this study my organisation had opened a 'guest house for carers'. This was literally what the title intimates, a place where carers could stay, while their loved one was cared for elsewhere. Although this initiative had won the national informal care prize in 2009, awarded by the State Secretary of VWS, and was providing welcome respite for some carers, the comments from carers in this project made it evident that this form of respite care, was very useful, it was not suitable for everyone. The data sets revealed that for some, being totally removed from their family unit caused more anxiety and stress than it relieved, the clearest example of this was given when one explained how she had felt when her husband had a short spell in hospital:

> *'i like the idea... they* [the hospital staff] *were very good... don't get me wrong... but I was afraid the whole time... they don't know him so well... I kept thinking... how they will explain things... what if he panics 'cos I'm not there... if he looks for me ... he won't find me... I was on edge ... until I got him home.. Then he took ages to settle'*

For these carers, finding a solution needed careful consideration, trying to work out which form of respite that they would accept. They wanted to continue to care but urgently need help before their own health deteriorated and they become one of the family units where the move into full time care arose because of the carer's exhaustion and inability to continue, rather the deterioration of the person with dementia, as one said:

> *'it's difficult … he' doesn't sleep well and can't seem to realise it's night time … wondering why it's dark…. Where am I…?'*

The pattern of disruption meant they started each new day already tired. They accepted that those with dementia sometimes get up in the middle of the nigh (as the example above indicates), looking for their family, or in other instances, convinced it was time for them to go to work, even when they had been retired for years. Others reported having to stop their loved one from setting out for the supermarket, convinved there was no food in the house and they *' must'* go and buy food. The long term result of such repeated nocturnal activities was that as one carer said *'I sleep with one eye open ... just in case'*, with many agreeing that even when their loved one did sleep through the night, they were afraid to relax in case they missed something. Interviewees reported *'catnapping'* when they could, but this did not replace what they described as *'a proper night's sleep'*. They knew that tiredness was impacting on their ability to continue to cope and care for their loved one. They were afraid of what would happen in the future if they became too tired to cope any longer. It was impossible to ignore the repeated plea of

> *'If I only could sleep for a couple of nights…… and not being disturbed by the nightly escapades from my husband……'*

That this need for sleep, was not just a local issue was evident in the government survey (Sociaal cultureel planbureau 2015) , which reported similar problems for participating carers. At this point I had to stop, reassess and then see what possible. I could see only one solution to help this group, and for this a new activity was needed. The design was influenced by the outcome of interviews who had repeatedly intimated that the main problem was not that their loved one had dementia, but that they needed a few nights of uninterrupted sleep. We called the project **'Volunteers in the Night'.** The title was chosen because it reflected exactly what the project was, and there could therefore be no confusion when it was introduced to the carers

Reflection

The nurse immediately wanted to find volunteers for the interviewed carers who were struggling because they were so terribly tired because of the many disturbances they lived with in the night hours.

The manager wanted a solution across the area in which the organisation provided care. This could not be a quick fix, there needed to be something that would last. These carers problems would need support for a long time, perhaps years. The solution had to be acceptable and sustainable. There was no extra finance, so the idea of volunteers appealed. Clearly, a new acivity was needed here... the manager needed to speak to the local councils and then set up a solution.

The researcher was realising that there needed to be a way to integrate all these 'new' activities into the main project as it was becoming clear that they were a direct result from the data collected.

The decision was made that this needed to be developed, not just in one local area, as the issue was found acress the region, so all the local councils in which the organisation delievered services were contacted. A meeting was set up between our roganisation and the council officers responsible for care, so that we could ask for support in this new project responding directly to the identified need that had formally emerged from the interviews.

The challenges of night confusion and the results of interupted sleep patters were known, but for the first time carer after carer had stated the same thing, and it had been formally recorded. This provided up to date evidence of the problem which we tabulated and used to ask for help from official groups. It was decided that a pilot prjoect would be established using volunteers who would be police checked and trained to provide support and care. Only once they had been certificated, having successfully completed appropriate training, would they be allocated into the project and able to relieve carers. The local councils were asked to pay for the training as it this would mean volunteers could be placed on a wider basis across local boundaries. It was also agreed that the ideal organisation to provide the training was the regional The Informal Care Foundation (SIZ) Twente, we are a recognised and trusted foundation with a remit of support for all carers, and acceptable to all who were willing to partner us in this pilot project.

It was seen as important that the volunteers themselves had support both as they trained, and then when they started their volunteer role. Therefore, once the training programme was written a cohort of fifteen volunteers were recruited. The training included: information about dementia as a phenomenon, the possible and to be expected behaviour components of people with dementia, the information about informal care and specially the role and needs of the carers. The information about the cooperation between professional care and the volunteer and the tasks and limits to the work were discussed. The volunteers were instructed about what to do in situations they couldn't handle. The training took place over a period of three months. It was seen as essential for them to have ongoing professional support once they started volunteering, and a system of 'supervision/support' was established for them all. This was possible because all family units involved were linked to mental health professionals, who accepted this role as part of their workload with the family.

Careful role descriptions were created so that the families knew exactly what to expect when ‘their’ volunteer joined them. We then looked at the families requesting volunteer support and the best way to ‘match’ the volunteer with the family. Following this, the certificated volunteers were introduced to the families and the pilot project was fully under way. This overall aim was to enable the carers to rest properly and be able to continue to provide the day time care, but volunteers could not be expected to work every night, so a system had to be developed
The next issue was how to introduce the new service, we knew some carers who could use the service, but it needed to be tested on a wider scale. The local paper had heard what we proposed and offered to run an article for us, at the end of which contact details would be given. They used a photograph of me going up stairs, symbolic (they said) of going up to be (see below).

7.13: Headline of Article in the local Newspaper

‘Fifteen night volunteers will relieve carers of their duties at night as a trial. The Informal Care Foundation (SIZ) Twente has trained and certificated fifteen volunteers to go into home of people with dementia, during the night hours to sit with the person with dementia, so their carer can rest and sleep

The response was immediate, and families who made contact were interviewed, the person with dementia assessed, medical approval was sought, and a care plan drawn up if the assessment suggested this volunteer scheme would benefit the carer and family unit. Some had welcomed the idea, but then found that they found it very difficult to receive a 'stranger' volunteer into their home. To address this we set up a system whereby they could meet at either the organisation, one of the day centre, or the local dementia café. They were given time to get to know each other, and only when both were comfortable did they proceed to home visits where they could meet and get to know the person with dementia. We incorporated this phased introduction into the project for all carers and their potential volunteers.

The pilot scheme went very well, and was formally evaluated after 16 weeks. Some caregivers were happy and relieved to have additional help and support that enabled them to cope with their self-adopted role of keeping their loved one in familiar surroundings. They saw

‘Volunteers at night’ as an unexpected but welcome solution *‘ ... I can keep my promise... she can stay with me ...’* However, the evaluation revealed that while that this solution did meet the needs of some of the carers, facilitating much needed rest, and relieving stress and anxiety, it was not suitable for every carer. Some on detailed assessment had needs that could be better addressed by other support services, and were therefore advised accordingly. This demonstrates the need for careful professional planning, it would have been easy to implement very quickly, but this would not have given time for a ‘cooling off’ period for all concerned. Also, listening to and assessing the family units was crucial as very careful ‘matching between volunteers and family units is essential.

At the start of the project, the availability of around 15 trained volunteers seemed sufficient to adequately organize support across the province, and the group of volunteers was therefore more regionally than locally oriented. This was appropriate as it enabled wider participation than a local resource would have done. Evaluation of the volunteers perspective was that they had found it rewarding but emotionally tiring and at times difficult, they valued the session of ‘supervision’ where they could de-brief and discuss any problems, and these have been continued. Also, they too needed time to rest and the project limits the number of nights they can act as a volunteer for their ’night family’.

As a result of the successful pilot, the ‘Night Volunteers project’ became the development of a regional volunteer network which has become embedded into the system of support for these overburdened caregivers during the night. However, just as with other activities initiated by this study, the volunteer project also started a chain of more actions. Once the decision had been made to continue and move the pilot study into a mainstream role, plans were made to increase recruitment and deploy more volunteers. It was accepted that this would take time as safeguarding was key, but a team was formed across the province to move things on. I was then free to look again at the interview transcripts, and reassess the requests for support and volunteer/ professional visits. Looking at the themes it was clear that some found the increasing care that they gave meant that they had had to give up hobbies they had always loved. Some wanted support so that they could have time for themselves within their home, but now found they could not continue as *‘it’s not safe to leave him alone...’*. as one reported:

> *‘I’ve always liked to play my accordion and would love to do it again .... but I can’t ... not by myself ...I can’t leave him ... I need some support……’*

This meant that for this group offers for a volunteer to visit during the night would not meet their needs, for them, another solution was needed. They needed a range of different daytime support, for some it meant somenone sitting with their loved one while the caregiver used a different room, but for others the support needed to give them the opportunity to meet with others who shared the same hobby.

It was at this point that the project for **‘art and vital day time activities’** was established . (see chapter 5) For this, help and support was needed from other organisations, and different groups were developed, based on the interests expressed by the caregivers. One example involved collaboration with a regional school of arts, they agreed to find space to start a day centre for caregivers of people with dementia, and previously had played a musical instrument. The art centre had all the facilities needed, and staff already employed who were willing to give their time, so that with the help of additional volunteers, both caregiver and their loved one could attend, and the caregiver could continue to play their musical instrument with help and guidance from professional music teachers, while the volunteers pro-vided activities for their loved one. In many instances this became a time where the music played included well known songs from previous decades, and the loved one would join in. The advantages of music therapy for those with dementia are well documented (Alzheimer Nederland 2018) and this project was seen as a ‘win-win’ activity. The caregiver could look forward to the sessions, and continue with a loved hobby, with help to extend their expertise, knowing that not only was their loved one was safe, s/he could join in an activity recognised as being enjoyable and benefical. As the sessions were carried out, it was obvious to many of the caregivers that’*’ he really looks forward to it...’* and *‘ she carries on singing aftwards and seems happier or calmer....’* For those that did ont want to join in, the volunteers would sit with them and seek out another activty that they were willing to join in, or in some instances, just keep them company. Other groups established include drawing and paining groups.

This form of support was developed and made available to a relatively small group of carers because it was specifically designed to meet identified need, to give carers the opportunity to continue their own hobbies, and to reduce isolation by placing them with others with similar interests. The collaboration with the school of arts became an example for collaboration with other organizations in the region, this has included sewing and quilting groups, and book clubs. The same system of organisation is used for them, but it has to be accepted that the needs are endless. Each time a new group form of support is initiated it raises the question of how far we can go in offering the nearly infinite types of tailormade support.

7.12: Respected partners in care

The data sets had clearly revealed just how important it was to be seen as a respected partner in the care of their loved one. They described how important it was for them to know what was happening and to be part of the decision making, with many reporting that

> *I have to 'fight' again and again with the professional caregivers, it seems as if their care never exactly matches my need for support.*

It was evident from the data that interviewees were unhappy with a system where they had little control over care plans and provision and were not always even told when changes in provision were going to arise. There was a sense of being disregarded, or of being ignored. They argued that they knew what they needed and understood the needs of their loved one better than the professionals

> *I'm the one who's there all the time.... but they don't ask... they don't listen... I've given up... now I just get on with it... but I don't know how long I can... it's getting harder...'*

This comment was typical of those who have been caring for a long time, and illustrates clearly the need for change. It is essential that these carers are accepted as key partners in care planning and provision, and receive the support they need if they are to continue to provide the long term crucial care which enables individuals with dementia to stay in their own homes. It was also clear that few understood exactly what support they could ask for, of where they could go to ask. In the light of this it had to be accepted that while the information toolkit was a valuable additional asset, its format was not necessarily seen as user friendly by all those who received it. A way had to be found that could be used by all informal caers to guide them through the journey that they were undertaking, and empower them to take more control of service provision, and through that be able to plan more for their own time and ultimately life activities.

7.13:The empowering of adult carers : A video of the journey

As the concept of a journey had become one of the defining elements of the study, it seemed the best analogy to use to provide user friendly information and guidance. The data gathered illustrates that while there are shared issues, just as the disease trajectory varies with the type of dementia, and the impact of any co-morbidities, so the actual journey is different for every single informal carer. Using the 'journey' as a concept from which to develop a framework for carers to use, it seemed most appropriate to use the train as a metaphor (as private transport does not necessarily follow standard stages). It was necessary to develop a programme that followed the pattern of a train journey, moving from a standing start at the first station, through the various stations until the endpoint of the journey is reached. This was used to illustrate the different phases followed by caregivers for those with dementia, starting with the diagnosis as the point at which the train is entered and the journey begins, and ending with the death of the loved one with dementia.

Talking with the interviewees, it had been apparent that they did not want '*just more stuff to read',* they wanted something easy to access and follow. Some mentioned videos, so it was decided that using current media possibilities an animated video/CD journey would be made. At each point there would be a narration to listen to, and information seen as relevant. This would be in two forms. One electronic and one hardcopy that they could then keep for referral. Also it had to be accepted that no everyone had the means to print documentation. Indeed, after completion it emerged that some watched it through the TV DVD options. Should this be their option in addition to seeing the information and gearing it described, it would be put into an annotated 'luggage set' or toolkit.

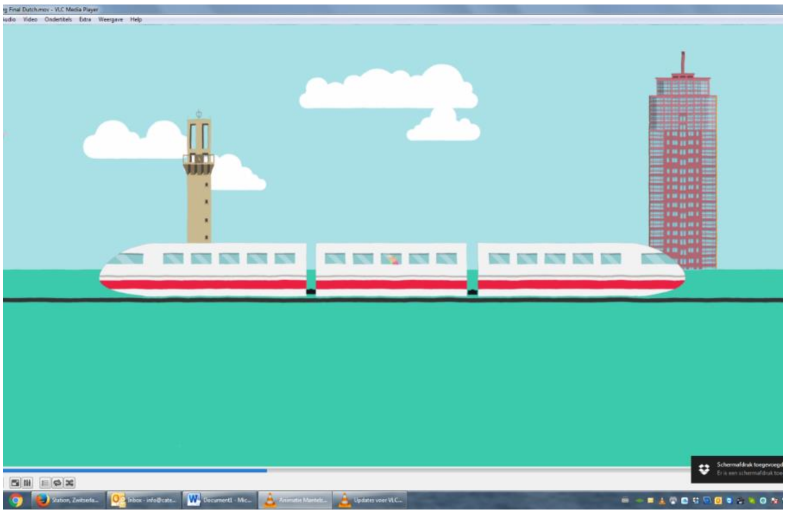
The vide film was based on 5 key issues that emerged from the iterative analysis process

1. People like to care for their loved ones but need support in caring
2. Caregivers need adequate information 'tailored'
3. Caregivers need different forms of respite care
4. Caregivers want approval and support
5. Caregivers want to be respected and fully-fledged partners in healthcare

The animation was developed in clearly listed separate sections to enable the carers to start, stop and repeat it as required. However, it was also seen as important that the structure also fitted with the approaches sued by healthcare professionals when working with their informal caregivers of people with dementia. They could then sit with the carers and work through it with them

The toolkit has been designed so that it can be adapted to give disease specific information for the different types of dementia,. To give them all the information about all types of dementia, would be frightening and daunting. They do not need to be put into the position where they have to look for their loved one's diagnosis and then work out what affects them and their loved one. They need to be able to focus on what affects them, not what happens to everyone with their different diagnoses. Therefore when the diagnosis is made the community services need to be informed of the diagnosis, the stage in the disease trajectory, and the behavioural patterns noted, and any diminution of cognition. Only that way can they protect those they work with, and help them work through and process the information they have been given. This can include helping them to come to terms with the loss of their plans and expectations for the future, as the interviews revealed that for many, it was at this point that they started to *'grieve for the life we won't have…. we planned our retirement… it's all gone now…. '*. For others it was evident that at this point they just wanted to know the professional was there as they struggled to come to terms with the unknown '*I can't take it in… yet…it's not real'*. For this group the package needed to be designed so that they could go slowly as they worked out what it really meant for them, their loved one, their whole family unit and their friends

An overview of the video film is given below, it gives two translated examples of the narrations given at every key point in the journey, and examples of these crucial times, but these are exemplars only, the whole film is interactive. The starting point of the journey is the train itself. Figure 1 the train for the journey



7.14 Still image of the video

This was seen as the point of diagnosis, when the individual first looks at the 'journey' about to begin for them and their loved one. The narration at this point sets the scene for the whole journey

> You are joining a journey with the many people in our country, who care for someone with dementia. This person could be your partner or husband, your father, mother, sibling or close friend. We use the words 'care for' because it is likely you are having to carry out some of the activities for daily living that your loved one can no longer carry out by themselves. We have used the term journey because the informal carers, we asked described their lives, by saying they felt they were on a journey, but they didn't know where they were going, or what to take with them. Some of you may have known there was something wrong, something wasn't right between you and your loved one. Now you have been given a diagnosis of dementia, it all changes, you know that there is one way back, you are beginning the journey of dementia care. To help you on this journey we have described a series of 'stations' where you will stop and can find out what this stage means, what the medical descriptions mean, and more information about the behaviour patterns you may see, the help you can ask for and how to move onwards. We have described this information and support as 'luggage' that you

take with you, and for each of you the luggage will be different, to meet your individual requirements. All the ‘luggage’ items has been developed from the interviews held with informal caregivers.

Examples of the Information included:

- On overview of the type of dementia their loved on has and a description of disease itself that leads to dementia
- The support possibilities for the informal carers themselves
- The support available for the young informal caregivers
- Information about what their province offers, in terms of services and access to appropriate professionals. This includes information on the case manager who will work with them, the centres of care in their area when they are open and what they offer
- How to take care of their own health
- Information what a care plan is, and how to develop one

Figure 2: The total train journey

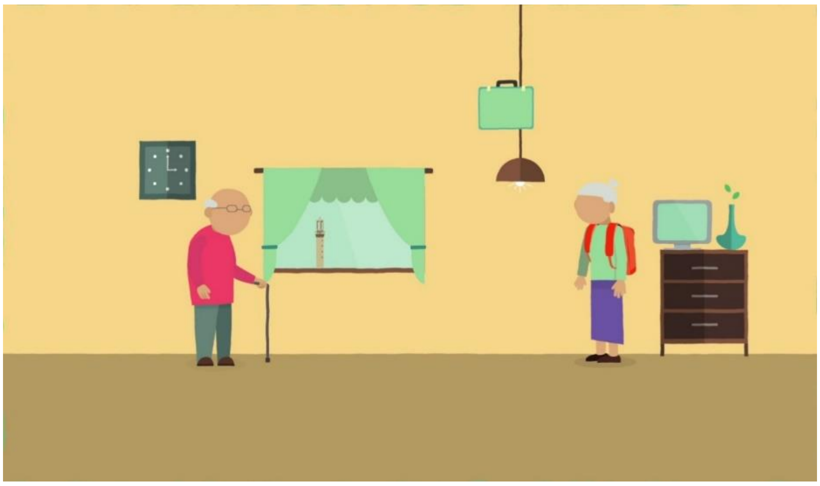
7.15 Still image of the video

Translation of the stations:

1. The diagnosis
2. Caring at home becomes harder (Dutch word means heavier)
3. The burden of the carer grows heavier
4. The patient moves into 24 hour care

The film continues, but moves into the home of the patient and his family, and you see the carer has collected the first ‘piece of luggage’, the backpack.

Figure 3: Setting out on the journey collecting the first luggage



7.16 Still image of the video

The narration continues

> You have now accepted the diagnosis and togetheryou are starting to plan for your lives together. You know your loved one will need increasing help, you have looked at the information you have been given and now you neeed to sit with one of the care managers to talk about what you are going to do. The people we spoke to said that at this tinme, they were sure they could cope, but they needed to have more detailed information to help plan how they could cope. You need to take care of yourself, to have time for yourself, so you need information about all the places and people who can help you. The information pack you have just been given has descriptions of local organisations you can contact, and what they offer. There is also information about the types of respite care possible, this is when your loved one can go to a safe environment for a short time to let you rest, because we know caring is very tiring. Or you can use the time to see the rest of your family without being concerned about your loved one all the time

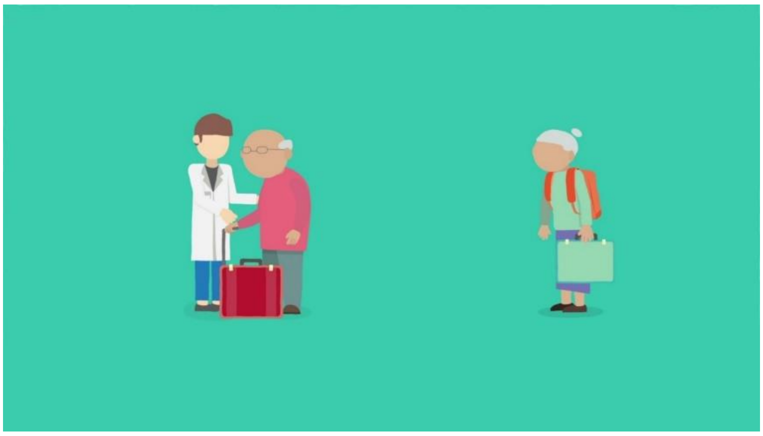
The information in the pack includes descriptions of

- Respite care such as
    - Day care
    - Deployment of a care volunteer
    - Hands in house
    - Respite days, weekends
    - Holiday options
    - Temporary stay, care sharing
- How to work and care
    - Emotional support
    - Education programmes to help understand the impact of dementia and how to cope
- Places to go and meet others
    - Alzheimer cafes
    - Meeting experiences ‘buddys’, people who have ha, or are currently carers for people with dementia
    - Discussion groups for family carers

Each type of care has been explained in the pack, as well as how to choose which one is suitable for each family unit. There are guidelines on how to access them and how much financial support (if any) is available. All the information sections have contact details for phone and email.

The video film returns to the train journey and shows another picture, as the train reaches the next station, but now it shows that the carer has a suitcase as well as the back pack, and again there is narration and an accompanying information pack, but here the narration talks about how life has changed. It uses examples from the interviews to talk about the challenges of caring at this stage, where the loved one needs much more care, and there is far less time for the carers themselves. It uses the terms given by interviewees, that the burden has become so heavy that it is *'almost unbearable'* and that day by day it gets harder to cope. The carer needs recognition and support, as do the people who are close, the immediate family, children, friends and neighbours. All who are involved in supporting the carer, and who offer care and/or support the carer and their loved one. As this stage, there needs to be a care and support plan for the entire household in which everyone has their own role and place and has their own network of support. All those involved need to know that they are not alone on their journey!

By now the film shows that there are two suitcases and the backpack, as burden gets heavier and more devcisions have to be made. Dilemmas begin to emerge, as the carer asks themself how long they can cope, how they can reconcile this struggle with the promise they made when they were first told their loved one had dementia. For some there is *'such a feeling of guilt'*, and this needs to be understood as acceptance begins to dawn that they will not be able cope *'for ever'*. The narration explains, using examples from the interviews that they should not feel guilty, but accept that they have done their best. They now need in an easily accessible format the information about the different types of care they could consider for their loved one. The need to know the advantages and limitations of the different types of care. They also need to realise that as their loved one needs more care, it signals a permanent change in their loved one's awareness and understanding of their family and surroundings. In the video film, the loved one is next seen with a professional healthcare worker, taking one case with him, while the carer keeps the other and the back pack, as all the information will still be needed.



7.17 Still image of the video

The information pack includes

- Information about the long term effects of caring
- The involvement of sources of additional help, often from a voluntary organisation such as
    - A caring volunteer
    - Day care leisure opportunities
    - Hands in house
- Coping with guilt, as the time for permanent care arises
- Choosing a place for the loved one to go to, and what that means
- Making the final decision about the loved one leaving home

Following this final stop, symboling the move into care, the train divides, with the loved one in one train, and the carer in the train on the other track. For the carer this is difficult to watch, it makes it clear that their life has seaprated and divided from their one they love. Inevitably at this stage, many carers begin to ask themselves why they couldn't cope for longer, and they need to know who they can contact for support. They also need to to think about their changed life. They will have so much more time on their hands. The interviews revealed that for some this was a time when they *'felt so lost ... and alone... I keep thinking where is he... I should be looking after him...'* They find it hard to adjust and move on as over time caring had become their whole way of life, and now overnight it *' had just gone...'* For some, there is also the fear that now they are not lving together, their loved one will no longer recognise them when they visit. This is a time when the support needs to incease irs focus on the family members, especially the main carer. They need to be given the opportunity to decide what role they want to play as they re-adjust to what equates in the eyes of some carers to *'being single again... but my wife is still living... we should be together...'* Some of those interviewed had found that for them, the best thing to do was to give advice and guidance to those still caring, to act as 'buddies', providing a listening ear and *'friendly face...'*.

However, it is important that such activities are not lightly undertaken as often when a loved one goes into care it is because the carer is exhausted. They need time and support to recover, before they can help others. It is also important that they do not use volunteer activities to fill the void that the loved one going into care has caused. They need information on adjusting to change, as well as all the information about advanced disease trajectories, long term care and the long term effect of caring on the individual.

The information includes

- Sources of advice and support
    - Information and guidance about letting go
    - Self help groups and support
- How to join an education programme the Art of Caring and Release
- Choosing the role to play as a caregiver
    - Information about rights and responsibilities with a loved one with dementia
    - Volunteering
- Information about health insurance and possible changes following their changed home circumstances
- Information about professional home support

As the train journey draws to a close, the loved one is no longer visible, by the arrival at the final station it is evident that the loved one has died, this brings an end to the informal care, but in addition to information, the suitcase is crammed full of experiences, knowledge and memories. The carer needs to take time to think and reflect on what was good as well as what was lost. The interviewees reported that *'it really helps… that I can help someone else… so they won't feel as I did…'* Other carers can learn from shared experiences, but for the loved one there may always be some regrets, these need to be discussed before the individual can move one.

In summary, although the journey will be different for all carers, recognisable stations are always passed. Using this video with the interviewees, they were clear that within this video they could recognize their own journey, they openly stated that they believed that this will help carer's feel supported and recognized. The plan is that this will be made available to all caregivers, and together with the carer, the professional supporters go work through the various steps shown in the video to give a complete overview of all conceivable support options. The train journey makes clear how the future *may* develop, but does not have to be watched all at once, carers can choose whether to see it all or go slowly through it stop by step. Based on this complete overview, carers will be able to access the appropriate information at each stage of their journey, can consider these and then with their professional carer look at the family care plan, identifying the role they want to play, and the help they need. They can use the video as a way to think and plan for their future as they slowly move towards each of the individual stations on the journey. By helping them do this, it facilitates each caregiver taking greater control over the care and support offered and provided. This will begin the process of empowerment, so essential if the caregiver is to traverse the journey formulating their own choices and emerging at the end with minimal regrets and accepting that they did all they could.

7.14:This became the prelude to the third new road: Training the professionals

One of the challenges revealed by respondents was their relationship with professional service providers. Yet it there is a wealth of research indicating the problems that are faced by carers, and the importance of professional help to support and guide them as they face challenge after challenge (CBS, 2015). In interview and interview, and in the focus groups, as the second road has illustrated:

> *'they don't listen ....I feel left out... they make the decisions ... without me saying what I want for him...'*

and

> *'I never seem to get anywhere...'*

Repeatedly they argued that they needed to be ore included and that while they accepted that professionals understand the disease trajectory, they know far less about the individuals and very little about the carer. Some carers felt

> *'I'm just left out... no one cares how I feel... it's all about her* [wife] *... it's as if I don't matter at all... but I need support...'*

and

> *'we talk about him* [husband] *... and then they leave... it's not better with the doctors... they ask but they don't listen... I and trying to explain and they've moved on... '*

The quotes given above exemplify how the carers felt. They were angry, but didn't know how to change things. They wanted to be involved and they wanted to lead care plans for their loved one, but felt disregarded, and as previous sections have shown they believed that they had been

> *'told off for making a fuss... the suggestion was that it was me... it was my problem... I was " imagining" things'*

It has to be a cause for concern that so many of them had *'given up'* expecting to be listened to, they had resigned themselves to the status quo, and were '*struggling on alone'.* They hadn't even been able to discuss their concern and anxiety as they saw what was happening to their loved one. Nor had they been able to express feelings of guilt for things they hadn't been able to do, or the resentment that they felt, sometimes against '*life'* and sometimes against their loved one. If these comments and views are reflective of this community as a whole then this is an indictment of the professional response to these carers. There are around 200,000 informal caregivers living in Twente, of which 28,000 are estimated to be struggling (Informele hulp, wie doet er wat? SCP 2015). Government reports suggest that almost 10,000 of them are not accessing help, some being so overburdened that they have not time to try, and others who do not know who to ask for what (Informele hulp, wie doet er wat? SCP 2015). If this essential group are to continue to provide 24 hour care and support, they must be able to access professionals who will listen to them and respond appropriately.

It has to be accepted that the professional service providers are under immense and increasing pressure. On the one hand because there is an explosive increase in health care demands due to the aging of society, with its increasing numbers of patients with co-morbidites, and rising incidence of dementia. More and more family members are having to take on the role of a carer, and the field of dementia care is no exception. Currently in all fields, one in four inhabitants is a caregiver, soon this number will rise to one in three! (Voor elkaar SCP 2017) The negative relationship between professional and carer that emrged in all data sets, cannot be ignored, it has to be urgently addressed, and ways found to improve the professional-patient professional relationship. Only if informal carers continue to deliver such devoted and loving care will it be possible for many of the high numbers of older people with dementia to remain in their own familiar settings surround by their families. On a practical note, without this informal army keeping loved ones at home, health care costs would rise exponentially, causing major constraints across the sector as a whole (Wie doet er wat? SCP 2015). To prevent this, it is essential that the relationships between professionals and carers dramatically improve, but for this to happen, there needs to be a way to enable the professionals to gain insight into and appreciate the very special roles played by informal /family carers.

Some interviewees reported that the problems with professionals extended from their personal challenge of being *'ignored'*, but included the shock they felt when they realised that because they were not seen as partners in planning care, their loved one now had to *'try to fit in'* to established systems build around the organisation, and not round the individual. This was not a universal finding, there were some examples of excellent care and support. Nevertheless, the reported loss of individuality occurred frequently. Carers interviewed reported seeing their loved one, whom they had thought was going to receive appropriate help and care now restricted and in some ways diminished by the need for care activities to be organised found specific times of availability of staff, and not individuality. This added to their distress, and if not addressed could leave them with an increased negative perception both of professional services and of the situation in which they found themselves. Then too, the care offered, fitted within the working method of the home care organization, but for the carers, this did not always seem to be appropriate to the needs of the person

> *'... they try...but... it's not what he's used to... sometimes he gets agitated ... he wants to do things NOW and I have to say wait... they won't be long... '*

Tailor-making individual care is difficult, because of time and resource constraints, but the inability to do this can increase the challenges for the carer.

In addition, the data revealed the carers often do not not feel recognized as serious partners in care. Precisely because the carers tended to be exhausted from caring, their intial response to being given help and support was to be happy that the burden of care had been lifted from their shoulders. However, as time went on and they began to recover they saw things differently, care had been taken over by the professionals, who as a result saw themselves as taking the lead in the life of the loved one. This is an important function of care, but a way needs to be found for the informal carer to participate in the care of their loved one. Home care has planned care and for them it is organisationally difficult to constantly change the supply of care, in line with the needs of the carer. This causes tension between the carer and the home care employees.

> *'i feel like ... I almost have to fight with them* [professionals] *... to get the support we need every time it's the same...'*

The challenge is that the professionals believe that they are offering good care. In their eyes, they are giving the support that the carer has requested. However, they are missing the contradiction that arises when carers have to accept that they cannot cope alone, but believe that the professionals cannot offer the standard of care that they (the carer) can. For the carer, whatever they see was not of their choice, they see good care, but not the care they as a partner, parent or sibling couls give with the love, to the one they love.

It was in the light of the carers wishes and concerns that it was decided that there needed to be a new road, one that prepared the healthcare professionals to see and understnd how rhe carers felt, to learn to work in partnership with them, sharing care planning and implementation. They need to see with the eyes of the carer, to recognsie and accept that what in theory seems in ideal, may not in practice be the best solution. Just as the carer gives up soem autonomy when they ask for help, so the professional too needs to relinquish some of their professional autonomy, and accept that while they may have profeasional knowledge and expertise, this is only one part of the equation of care.

The decision was therefore made, that this third new road, needed to be one that developed resources and training materials for the professionals, to help them work more effetively with both informal carers and their loved ones with dementia. The traditional approach of focusing on the patient with the wife, husband or other carer seen as an adjunct, not the core of care is not appropriate. Programmes and activities needed to be developed to help the professionals move from the provision of individual care, to working in partnership, to provide holistic, family unit centred care with with the aim of supporting and strengthening the whole family unit.

The starting point, was that the informal carers needed to be recognsied and included in all aspects of care planning. For this to happen, the professionals needed to understand how the informal carers felt, and I needed to find a way for the current approach to be transformed to meet the needs of this very special group. It was decided that a radical rethink was necessary. The study data had shown almost unanimously that there was a hierarchical position, with the informal carers believing that the professionals *'have the power...'* and that there was no way to change the situation. They had tried, but because they had not found a way to bring about change, they felt dis-enfranchised and had *'given up trying'.* It seemed that the best way to change this was to develop an education and training package that could be used with the professionals to help them accept the need to change their approach to deliver integrated care which met equally, the needs of the carers as well as the patients.

Having decided the way forward it seemd that the most important thing to do was to provide them with a resource that they could use in the training programme and afterwards. The most approprite format appeared to be an **'Informal Care for Professionals Training Manual'.**

This was designed to be the core of the whole programme. After re-visiting the transcripts, reviewing again government policy and documentation the education and training programme was designed. Initally the plan was only for face-to face training but I quickly realised that if it was also made in digital form, it could be used on a wider basis, and therefore all materials have been developed for use in both formats.

The programme was developed with three aims

- To increase awareness and understanding of the life of a caregiver
- Promote cooperation between professional care and informal care (informal carers and care volunteers
- Provide healthcare professionals with tools to fulfill the various roles that are required in the light of the WMO (2007)

In planning the manual, data from the study played a key role, it was evident there needed to be a paradigm shift in the approaches used by professionals. There is a wealth of education material regarding principles of adults learning (Edwards R, et al 2013) the factors that can positively, or negatively impact on what is retained (Seel N, - 2011) and strategies for reflecting on practice (Taylor K. et al, 2016) Studying these, it was evident that a didactic teaching approach would extend knowledge, but would not provide the opportunites for discussion and exchange of ideas neccessary to enable professionals to reflect on what they usually did in their professional role, while considering the current situation as described by informal carers. Therefore, an interactive education approach was chosen, and the programme designed to be used with small groups, rather than more traditional large lecture based sessions (Rothwell J, 2008) The training manual was designed in three sections, each one addressing one the aims given above.

The majority of interviewees had developed a negative perception of healthcare professionals that, based on their comments, was adversley affecting professional working relationships. They, the carers, saw '*no point...'* in asking for support for themsleves or help for their loved one. The quote given previously pointing out that they felt *'always had to fight for everything'* was typical and repeated a multitude of times. Looking closely at the transcripts, this view seemed to be rooted in a believe that the healthcare professionals just *'don't understand what it's really like...'* . However, for meaningful professional relationships to be developed, there needs to be mutual understanding and acceptance, each side needs to take time to look at things from the perspective of the 'other'. Only that way can concerns be fully shared, and used to support the development of a way forward, that respects all involved (Tonkens E et al, , Op zoek naar weerkaatst plezier, 2009) A wealth rich indepth data had been willingly shared, much of it illustrating life and the challenges faced by the informal carers, and the impact of dementia on the whole family. It seemed that using this anonymised data to create a series of scenarios and case studies covering the disease trajectory from diagnosis, through to full-time care and ultimately end of life would provide appropriate discussion points for the programme. Questions focusing on key issues of providing care for a loved one living with dementia, as described by the carers, were designed to be attached to each one for use in teaching sessions. Based on examples of the lived experience, and including different causes of dementia, these have been designed to help the professionals to 'look into' the lives of informal carers. To facilitate discussion, while protecting confidentiality, small spoken vignettes have been developed for each scenario, these, spoken by members of the organisation, bring the scenario or case study to life. They could be used on-line to support the early part of the programme, or watched live as part of the teaching programme.

7.18 Photo example of small group work using the training manual

The second part of this first section of the education programme, re-uses the scenaries, but this time to consider what motives informal carers, and what could beaffecting their ability to cope, and to continue in their chosen role. It moves on to focus on quotes from the data which clearly illustrate the perceptions of informal carers when they come into contact with the professionals as they try to access and use professional services. As with the first section, some of these have been spoken to increase the reality of the carers perceptions. Reading the comments does have an impact on the reader, but the spoken mini clips, when tried with a pilot group the more interactive CD versions raised the level of discussion with the group exploring how these perceptions could have arisen, and how they might impact on access to services and the working relationships. The examples in this section have been designed to be used in the small groups, but with supervision from the programme tutorial team, to help as the discussion goes on to consider how these views could be addressed.

The second section of the programme has been designed to help professionals reflect upon the issue of professional cooperation, with other professionals, and with informal carers. It considers the different strategies of communication, how these can be used to promote partnership and to engender trust (Tonkens et al, , Op zoek naar weerkaatst plezier, p 88, Amsterdam 2009). It looks at why and how hierarchical realtionships can develop within professional service provision, and factors which may have either led to or pre-disposed the informal carer to feeling disempowered and dismissed. It looks at situations that were reported where some interviewees reported, having felt they were over-reacting *'...he was saying it was me... '* or that they were wasting the time of the professional *' I was making a fuss when there was noting wrong'.* Following this type of consultation, the informal carers stated that they were reluctant to raise issues again, and from this reluctance, the distance between professional and informal carer increased, until ultimately, as evidenced in this study, they had *'given up...'*. The teaching sessions in this section have been designed to include interactive tutoral sessions, and roleplay to review and reflect on how communication styles impact on professional relationshiops (refs)

7.19 Photo: interactive small group work

From this section, the programme moves into the final section which has been designed to enable professionals to enhance their skills in recognising the needs of informal carers, and learn to communicate effectively with them. With diseases such as dementia, it is essential that the implications of the disease trajectory and possible treatments are fully discussed with the informal caregiver, and that at every stage strategies of support are integrated into care plans. Where this doesn't happen as this interviewee stated when the hospital decided to try a new drug to reduce agitation:

> *'it was so difficult... I didn't know whether it was him... was this now it ... he seemed different but we know he will get worse...'*

The informal carer didn't know whether to contact the professionals or to '*struggle on'* she wasn't sure whether the changes she saw were drug side effects or progression in the disease. Hence she didn't know how to respond, an unacceptable situation for the whole family unit, and one which could have been avoided with more effective communication between all concerned. In the light of episodes such as this, health care professionals need to reflect on their own strengths and weaknesses as practitioners. The role of empowerment in increasing resilience, and hence enabling the informal carer to continue for longer in their challenging but very important role is known (SCP, 2017). However, there is much less guidance on how to adapt information sharing to reduce the traditional hierarchical approach to health care in which the professionals (particularly doctors) are accepted as experts who pronounce diagnoses and treatment. There needs to be a move to change this, and for health care professionals to become guides and expert partners through the care process, working with the patient and where appropriate caregiver, to deliver the best possible treatment options. It is accepted that mental health practitioners have themselves to be in supervision, but this programme argues that this should include considering how to make an internal shift in themselves. They need to alter their approach to practice to achieve the measures expected from implementation of the WMO (2007), whereby the patient and/or carer are seen as lead partners, supported and underpinned by professional services, rather than junior partners led by the professionals. Part of this entails all professionals in the multi-disciplinary team working with their peers to reflect on all aspects of their practice, including how their training and self perceptions have impacted on the communication styles they use.

Having completed the planned programme, we suddenly realised that there was something missing. When a colleague and I searched all the available information for the second new road, we had found compiling it into a useful resource for the videa difficult. On consideration we decided that the pack for that needed to be adapted intoa toolkit to support this education programme. We compiled it into a Toolkit for professionals (see appendix 6) , this was a much more extensive version, designed this time proimarily for the professional to use to identify appropriate resources to take to share with the informal carers. This supplemented the training manual and included all national organisations, anda separate section with great detail of all resources in the province of Twente, including contatc details and times of opening. It was accepted that not everyone would have copies of the full training manual with them at all times and therefore core information from that was extracted and sections regarding the lives of informal carers, their experiences, the reasons why they were so motivated to care and the most popular informal carer local support options were added.

This was financed by the local and provincial councils, and formally presented to the care organisations on the ‘Day of the informal carers’. This is always on November 10th, and the presentation was made in the cityhall of one of the local councils in Twente. Once the first toolkit was complete, others were developedfor all other local areas in the province.

The final step in education, was to approach the umbreall organisation for **Training of future healthcare professionals.** This was becuase there was one group who would benefit from additional support. In the Netherlands 1 in 9 students have to combine caring activites with their studies (Boer, A. De, Oudijk, D. & Tielen, L. (2012). The aim was to ask them to develop a Support/Information Centre for Informal Carers enrolled on a study programme. Members from this group could go to them for information and guidance on the possibilities of being supported. The idea was accepted, and the centre is being developed within the College. In addition to students, it will have a section for teachers who are informal carers, study areas for healthcare students, and qualified professionals. It will also look to develop a centre for research and project development in informal care.

Once the training programme and manual were complete, the programme could bepiloted. As with other activities there was major local, regional and Government interest. We were asked to further develop this into a national programme which could be used by the Ministry VWS. This entailed adding a resource textbook to support the education programme. The training manual and tool kit have been revised and now include the informal carers support plan. To my amazement, the whole package has been accepted by the Ministry, and this summer it will become part of their national training initiative, starting in Twente summer 2020. Plans were in place for a formal national handover in July 2020, but in the light of the COVID-19 pandemic, this will be communted into a virtual event.

The book cover:

Translation = Education programme for professionals on informal carer support

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Chapter 1: knowledge about informal care, the current situation
Chapter 2: motives and perception of informal care (ers) and support

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Section 3
Chapter 4: from taking care of ...to supporting:
a shift in intention, a change in role as a healthcare professional
Chapter 5: A shift in support requires a shift in YOURSELF
Chapter 6: realizing the intention, how can we move forward and do this?

7.20 The manual (book) for training the professionals

7.15:Initial orientation with ICT providers

With all elements in place contact was made with local ITC providers because the resources will need regular updating. Also there is now a digital file for recording the care processes and recommendations of the professional. These now a government statement that these need to be updated and expanded to include a section in which a formal support plan for the informal carer has to be recorded. The aim is to develop one integral file for patient, carer and professionals, we have worked with the ITC providers to develop this and pilot it with informal carers. The pilot will be evaluated and the final forms and files added to the training programme.

7.21: Photo: completing the informal carer support plan

7.16: The fourth road: empowering the community

Having considered the young people. The adult carers and the rpofessionals, the only area not addressed was the place where the informal carers reside, and therefore the fourth new road had to be for the community. Only when social and political changes processes are in place for the community as a whole, can the individual groups and populations as a whole gain more influence over their health and quality of life. The whole aim of the WMO (2007), implemented in 2015, was to move the focus from acute care to community care, to make communites take resonsibility for their own health. However, it was recognised, that empowering the community is complex, it is not enough to change policies, strategies have to be developed to encourage individuals and groups whio have previously not had power or ability to influence processes individually, in a group or as a whole community. Measures have to be found to focus on mobilising group responses, developing cohesion among members and making sure that health messages are disseminated in a format that is easily accessible and appropriate. The WMO (2007, 2015) use the concept of community here broadly, recognising that organisations, including thos involved in healthcare can also be percieved as communities in their own right. Just like personal empowerment, community empowerment can also be divided into 3 elements.

- Shared experiences, for instance a community of informal carers within a town, a groups sharing the same beliefs and attitudes
- Critical awareness of insight into pwer relations or gaols of the community
- Behaviour as social participationand the set-up of cooperative relations. This may include preconditions for acheiving empowerment, such as adjusting the physical environent, adapting legislation, regulations and agreed procedures.

For the health promoter, and/or the professional care provider, this means making use of what is already available in terms of community strengths and skills, and identifying what measures would develop them further. People from within specific target groups are encouraged by health promoters to use their own strengths and possibilitie, to take responsibility for their own health and living environment. Alternatives can also be offered for practices, if people can learn different ways to deal with challenging situations (Jacobs, et al. 2005). Recognition of the need to work with the community and encourage them to look for ways to empower subgroups, and enable them to decide what they need for themselves will have an important place in the training of professionals to support carers.

7.16.1:Veurmekaar, the development of a movement

In terms of dementia care, the main challenge is that informal carers are so busy, just trying to support their loved one, that they have little time to be involved in community measures. Yet having developed and reviewed the other activities, it was evident that while some of them such as the dementia cafes, and other hobby activities, did have some impact on members living in the community, this was not enough to help the community members increase their autonomy and work together. A way needed to be found to link the individual measures together to facilitate the development of community activities. In consequence, it was decided that a new project, Veurmekaar or 'Good for each other' should be developed and rolled out. Funded by the Province of Overijssel, the adjacent province to Twente, the aim was to involve neighborhoods, streets and other communities in looking for ways to link with informal carers. To find ways for them to gain increased awarenss and insight into the life that informal carers experience every day as they care for their loved one. It was hoped that with increased understanding the community would start to work together, to use its 'unused care force' to support the informal carers in their daily activities. This is comparable to the dementia friends in the UK, volunteers band together to try to support the informal carers in their local area. Part of the Wmo policy was to help members of a society accept that caring for each other, not only consists of using professional care services, but that first and foremost, communities need to look for self-care options that can help, using the commitment of the community.

Veurmekaar means thinking differently about care and well-being

What Veurmekaar wants to bring for each other in society means a huge change in thinking. This paradigm shift does not only apply to the citizens in society, but also to the professionals. They are the ones who, on behalf of organizations, their organizations, meet informal caregivers and offer support and care. We know (also from this study) that the care offered is not always in line with the interests of the informal caregivers. One of the issues is the contact with the professional care provider and the council services Instead of experiencing support in their role as care providers, they report having the feeling that they have to subordinate their own wishes to those of the professional and statutory organisations

> *'I always get the feeling… that I am asking something for myself …* [and not my partner] *that I have to fight to get the care organized… in a way that it is helpful for me ...'*

And

> *'I always have to adapt to their* [the professionals] *rules or policies … they don't listen carefully to me … while I still know best what the care for my neighbour should be '*

What actually happens is that professional service providers, do not seethe informal carers as full partners in healthcare. Instead, they are primarily focused o following their own policies and procedures, expecting everyone to adapt to this, instead of trying to fit the care offered into the families' lives. Tis takes control away from the main caregiver. Veurmekaar has bee designed to change this situation through mutual agreement. The belief is that the management of informal care belongs to citizens themselves and not to councils and and health care professionals. If this project succeeds it will open up and activate a huge social source of care that currently is still left untapped. To do this, it will be necessary for Veurmekaar to explicitly work with professional caregivers and other statutory services, to help develop the needed paradigm shift, through awareness and staff development and training.

The need to do this has never become clearer than it is today, with the COVIID-19 pandemic, with the whole country locked down, each community is well aware that it has to work together, caring for each other is now crucial. No other help is possible as health services are stretched beyond belief. The motto of the Dutch government is therefore: 'Only together can we get Corona under control'. Whilst this an acute crisis, the sentiment of caring for, and working with each other is essential, prior to this health services were already struggling with the rising health service demands. I am arguing that what many of the informal carers need is not another illness based service, but access to support from peers and colleagues, they need to feel that life can still be lived with socal contacts and some time for themselves. With this in mind, the project Veurmekaar, which means good for one another, was planned and launched.

The theory is that only when this is no longer sufficient, should professional care be brought in, and used to supplement and extend what is not possible for the carer and the community. However, while in theory this should be possible, the reality is that over the previous three to four decades, in the Netherlands, care has been centralised, taken from the family and community, with specialist community health services delivered by professional carers. As a result society has developed structures whereby health and health care are seen as the responsibility of the state and not the individual (Duyvendak. J.W. 2017)). There is a belief that the these health professionals (particularly doctors) are the experts and *'and know best'.* This has led to a passive approach to health, where individuals follow medical advice, but on the whole do not actively seek to carry out health promoting activities (Horstman.K., Houtepen.R, Worstelen met gezond leven, 2005)). For the community to increase control over its own health, this approach to health has to change. It has to be said that this is not just a Dutch problem, it is a common finding across many high income countries. The problem is that as the population ages, and medical advance means more advanced care is possible, the inceasing numbers of individuals with co-morbidities is rising exponentially, and (as cited earlier), this includes the incidence and prevalence of dementia (C. Jonker, F.R.J. Verhey, J.P.J. Slaets - 2010). However, for this group of patients there is an added challenge, the medicalisation of health (Illich .I, Limits to Medicine, 1995) has led to the separation of those who are ill from the rest of society, and in consequence many of the interviewees reported feeling isolated, not just becuase of their role as a carer but because

> *'they* [friends and family] *are uncomfotable.. they don't know... what to do... when he's confused... and doesn't know them... or he just sits '*

She went on to say

> *'after a while ... they stopped coming... and i was embarrassed .. so I just left it'*

Reversing this type of situation is difficult, but efforts have to be made to re-unite the community, to help it care for itself. Advocacy is developing into a citizens' movement for one to one informal care providers. The organisation of the activities is initially placed with SIZ Twente as 'parent organization'. This is a logical first step in view of the more than 35-year experience that SIZ Twente has in the region as an organization for informal care: the carer support and the use of voluntary home help. Anyone who subscribes to the vision can join Veurmekaar. To make this movement self-sufficient, we think of a contribution, on an annual basis, in the form of individual or collective subscriptions.

In the first case, an informal caregiver individually takes out a subscription. In the second case, an organization does this on behalf of its employees or members. Veurmekaar subscribers can use a package of services provided by the Veurmekaar work organisation. This work organisation primarily consists of professional workers from SIZ Twente. Over time, it is hoped that more and more volunteers will be able to support informal caregivers (citizens), they will supplement and support the main professional and informal carers. Hence the professional will be staffing the work organisation themselves, although support from professional forces will always be needed to a certain extent. In this way the plan is to gradually hand over care to the main target group of the movement, the informal caregivers, it is hoped that ultimately take control of the content of all Veurmekaar's activities. They already have the most important voice in the project.

Reason and goal ‘for each other’

Volunteer care is a choice. Volunteers choose to join the group, initially, there is no emotional bond, they provide their care for a limited number of hours and can stop doing so at any point, it their own choice. Care volunteers work witin a formal structure with agreed activities, and never perform nursing activities. Within our practice, it is possible to see that as the project grows care from informal carers and volunteer carers are increasingly intertwined. Every effort has been made to differentiate the terms used, with the term informal care used to identify all activities that are carried out by informal carers, and family members, and includes both care and well-being. However, it excludes care performed by professional service providers.

In its policy direction, the government has opted for the maximum use of self-care: people take care of themselves and then each other in their own environment. They organise as much care as possible for themelves in and with their own environment using their own (social) network and remain as independent as possible from the government, although aware of the possibilities that professional care offers. Only when self-care is inadequate should families ask for support from the health care srvices and local socal sevices organised by local councils. These have an important role to play in supporting informal caregivers, laid down in the Social Support Act (Wmo). The Long-term Care Act (Wlz) and the Healthcare Insurance Act (Zvw) also provide opportunities for care or part of the care to be taken over by professionals (see chapter 2).

Briefly, the policy plans for the future of care in our society argue that it shouls be as follows: individuals arrange care for themselves and their relatives, doing as much as they can for themselves, because that is what they want most, only calling on professional support they have exhausted their own recources. The idea of this, is seen as a healthy development that fits the movement towards a more and more participative society. At the same time, this development requires a major shift in thinking and doing by the community, agencies and professional forces in care and welfare. At present this is still in its infancy, but slowly the country is moving towards this approach. Ultimately, communities will organize this well, but today, they still need help. It is precisely for this reason that Veurmekaar arose: to make sure that the slow steps towards the self-care society were guided onwards. This was seen as an effective way to underpin community empowerment, as individuals (and not agencies with their professional views) learnt to work together. I, and my organisation, believed that it would be possible to develop informal care services over a period of 5 years in Twente, from a organisation led service into a citizens' movement that is self-sufficient, independent and an addition to formal professional care. This goal has been shared with members participating in 'Veurmekaar. Foremost, it is a movement of, for and by citizens whose goal is to maximize self-care and to keep control over the care and support provided by the council and health professionals for as long as possible in their own hands. This will makes Veurmekaar independent of municipal support and professional care. With its knowledge and experience, SIZ Twente wants to initiate, organize and facilitate this movement, noce it is self-sufficient it will be formally handed over to the local communities.

Unused care power

There is still so much to be gained when it comes to caring power in our society that is not yet being used. The tailor-made support of informal care providers provides an extra amount of care. The use of people who have a disability themselves is also a way to appeal to extra care. The active approach of people with the question of whether they want to do something for a neighbour is to address unused care power. There are so many ways to think about involving citizens in caring for others. Everybody wants to invite, inspire and support people.

Positioning of Veurmekaar

We assume a certain degree of self-care that is present with every citizen. If people who want to be actively involved as informal caregivers in keeping their support and care in their own hands, they can call on Veurmekaar. Veurmekaar does not carry out the agenda of the municipalities or the care providers but of the informal care provider himself. Veurmekaar positions this precisely behind self-care on the line that runs from complete self-care through Veurmekaar to the guidance to municipal support and / or professional care. Even before the municipal support and or the professional care effort is on the agenda. This is necessary in order to have maximum grip and to maintain control over their own support and care, in order to remain in control if it goes. Figure 1 shows the intended position of citizens who need some help when having aself-care shortage.

Voordat burgers toegang zoeken tot professionele zorgverleners, kijken ze met behulp van Veurmekaar hoe ze zelf voor elkaar kunnen zorgen

Figuur – Beoogde positie van Veurmekaar

Figure 7.22 Intended position of Veurmekaar

Before citizens seek access to prefessional care providers they use Veurmekaar to see how they can take care of eachother first.

Empowering the community : an example of Comunity empowerment: For each other

In 5 jaar ontwikkelen we in Twente informele zorg tot een burgerbeweging die zelfvoorzienend en onafhankelijk is en aanvullend aan formele professionele zorg.

DOELSTELLINGEN

We bouwen stap voor stap een maatschappelijk systeem om zelfzorg steeds verder te versterken

We nemen burgers en professionele zorgverleners mee in deze informele zorgbeweging door middel van bewustzijnsontwikkeling en scholing

7.23 unused care power

This poster gives the name of he project and has been designed to raise interest and awareness, it gives the aims and states that the project is designed to help by neighbours to help neighbours. It was designed to be used either as a stand alone poster,or as part of a presentation. A summary of the main activities was collated onto a further three slides/poster. Information accompanying this, and given to interested parties states that:

In our society we need take care of each other wherever one of us needs help. We call that sharing and helping. This approach belongs to our society and is an important value. Sometimes people find themselves in the role of caring for a loved one for a long time, with the care becoming more and more intensive, we say the person has become an informal carer or Caregiver.

The motive is always the same, they love the person, so take care of them. It could be their partner, parents and/or child if he or she has a disability. Sometimes the worry from doing that starts to take over (too) large part of their own life and they start to struggle with a burden that grows heavier and heavier as time goes on.

When that happens, it is important that there is someone there to help. Could you be that someone? Do you have time to spare to help a neighbour? To support them so that they can continue to care for their loved one. Supported means in this case, to help the have links with a ‘normal’ life, so that theywill be able to continue to take care of their loved ones for as long as they want.

Do you have time to talk more about this helping your neighbours?

ONVOORWAARDELIJKHEID

De sleutel tot een succesvolle burgerbeweging voor informele zorg ligt in het begrip onvoorwaardelijkheid.

UITDELEN EN ONTVANGEN

Onvoorwaardelijkheid draait om het vermogen van mensen om te kunnen uitdelen zonder daar iets voor terug te verwachten en om het vermogen te kunnen ontvangen zonder daar iets voor terug te hoeven doen.

RELATIE IN PLAATS VAN TRANSACTIE

Voor elkaar zorgen is nooit een transactie van zorg van de een naar de ander. Het gaat altijd over het aangaan van een relatie voor kortere of langere tijd. Deze relatie wordt aangegaan vanuit liefde voor de ander (ik gun het jou) en niet vanuit een berekenende houding (voor wat hoort wat).

SOCIALE INNOVATIE

Veurmekaar betreft een sociale innovatie die de wijze waarop (informele) zorg nu georganiseerd is heroverweegt en toekomstbestendig maakt.

FLEXIBEL

We doen een groot beroep op de eigen verantwoordelijkheid, kennis en kunde van alle betrokkenen. Formele rollen en traditionele rolverdelingen worden bewust doorbroken.

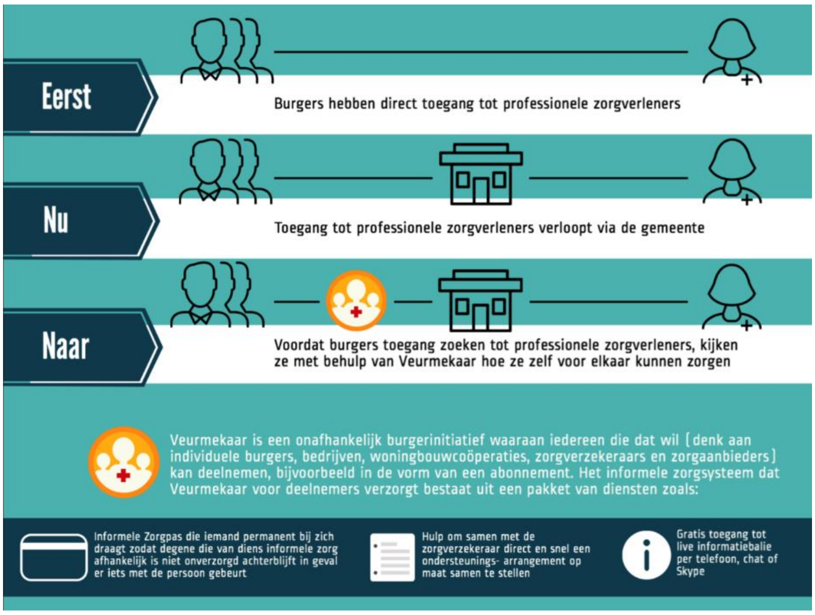
SAMEN

We laten zoveel mogelijk mensen dat doen waarin ze goed zijn, ongeacht hun formele rol.

SLIM

We kijken steeds met wie we kunnen samenwerken om onze ambities te vervullen. Onze onafhankelijkheid mag daarbij nooit in het geding komen.

And



Burgers hebben direct toegang tot professionele zorgverleners

Toegang tot professionele zorgverleners verloopt via de gemeente

Voordat burgers toegang zoeken tot professionele zorgverleners, kijken ze met behulp van Veurmekaar hoe ze zelf voor elkaar kunnen zorgen

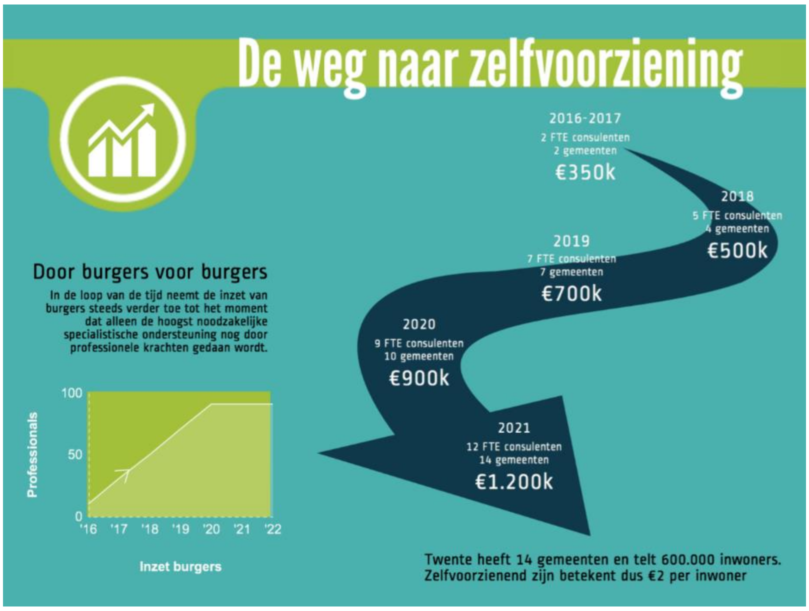
Veurmekaar is een onafhankelijk burgerinitiatief waaraan iedereen die dat wil [denk aan individuele burgers, bedrijven, woningbouwcoöperaties, zorgverzekeraars en zorgaanbieders] kan deelnemen, bijvoorbeeld in de vorm van een abonnement. Het informele zorgsysteem dat Veurmekaar voor deelnemers verzorgt bestaat uit een pakket van diensten zoals:

Informele Zorgpas die iemand permanent bij zich draagt zodat degene die van diens informele zorg afhankelijk is niet onverzorgd achterblijft in geval er iets met de persoon gebeurt

Hulp om samen met de zorgverzekeraar direct en snel een ondersteunings- arrangement op maat samen te stellen

Gratis toegang tot live informatiebalie per telefoon, chat of Skype

7.24 old situatio and new sitiation



In de loop van de tijd neemt de inzet van burgers steeds verder toe tot het moment dat alleen de hoogst noodzakelijke specialistische ondersteuning nog door professionele krachten gedaan wordt.

Twente heeft 14 gemeenten en telt 600.000 inwoners. Zelfvoorzienend zijn betekent dus €2 per inwoner

7.25 The way to self help

It was crucial that Veurmekaar's position was recognized by all professional partners and healthcare providers. Collaboration and good teamwork were essential as it meant a new focus on support and care, also for all professionals and professionals in training, now and in the future.

Embarrassment to ask for help and unconditionality

Within Dutch society the health care system must deal with a strong feeling of 'embarrassment in asking for help' which works as a kind of invisible threshold or barrier.

People do not like to ask someone else for help because they feel there is always a counter-performance to be delivered. It is easier to help someone else, because then people feel they do not have to answer the help by returning giving help to someone else. As a result, there are always more people who want to help another one than to ask for help for themselves. This also applies to informal care. People find it difficult to ask for help or support from someone from within their own network. The person seeking help finds that no personal consideration is offered, and that makes it difficult to ask questions, yet, asking for help and support an essential part of self-care. We must overcome this embarrassement for asking help. Personal reticence and reluctance to admit help is needed. To feel free to ask for help individuals need to trust that those consulted want to do something unconditionally to help. Unconditionality revolves around the ability of people to be able to give help and support without expecting anything in return and for those receiving the help, the ability to accept without having to do something in return. Just being grateful is enough.

From, for and by citizens: how are we going to design that exactly?

What exactly is offered and how it is organized must be the outcome of the request from the informal care providers themselves. Not just once, but permanently, every time they make contact. A panel of informal caregivers help plan for this, with an ever-changing staffing that can always indicate in a meeting or online what needs exist and how support this should be organized and therefore offered. In addition, so-called personas have been developed. A persona is an archetype of a user, or a characterization of a certain type of user in a given context. With the aid of the panel, we developed over time, an imaginary person who represents this situation of informal care for every specific context in which informal care takes place. Personas are an effective and inspiring means to develop new services that are closely related to the lives of real people, in this case informal caregivers who are subscribers to Veurmekaar.

The work organisation of Veurmekaar consists of informal care consultants who are supported where necessary (administration and organizational). We have as little overhead as possible. In business operations, in addition to the expertise of the current consultants (professionals), more and more consultants are being used who also have experience with informal care. Experts' expertise is a condition in the competency profiles of consultants. Within Veurmekaar, the focus is on the deployment of volunteers to give substance to the organization and support in informal care. This not only involves unpaid work in the form of a respite for a caregiver, but also the organization of the work so in the office. The search for experiential expertise also applies to volunteers. People who are (have been) active as caregivers themselves.

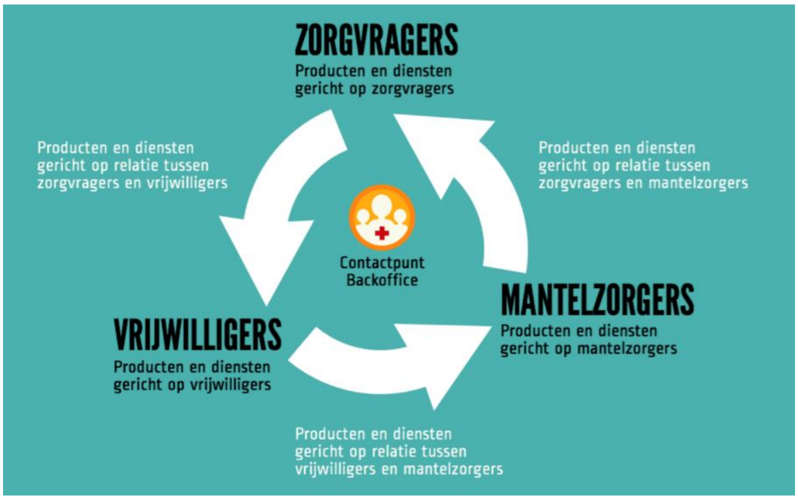
SIZ Twente acted as a parent organization when it came to starting the movement. The execution of the municipal agenda based on a subsidy relation (current core task) in addition to the content of the Veurmekaar movement is difficult to combine. Where SIZ Twente currently serves mainly on behalf of the agendas and interests of municipalities and healthcare providers, Veurmekaar stands next to the informal caregivers, looks after their interests and carries out their agenda. The chance of conflicts and conflicting interests is real and undesirable for all parties involved. In our opinion, the priority should always lie with the informal care provider and his interests. For this reason, Veurmekaar has been designed to become an independent entity after the start-up board and work organization are well established. Both the board (and supervisory board) and the set-up organization of Veurmekaar consist of people who are experts in the field of informal care. In the course of the next couple of years, privatization will have to be achieved. The expectation is that the formation of a separate entity and thus the separation of SIZ Twente will take place no sooner than 2021.

What does Veurmekaar do exactly?

Everybody has a range of possibilities with which the citizen can strengthenedand gain in self-reliance. By definition these are not the support options that are offered from the district teams of municipalities. These forms of support are seamlessly connected.

Information and advice within 24 hours on working days: via telephone contact, chat with an expert and or a skype call;
The use of an informal care broker who, within a short timeframe (for example, 3 x 24 hours on workdays), is able to line up and execute control issues together with the informal care provider: often an important condition to be able to start well as an informal caregiver
Rapid deployment of and access to various possibilities for respite facilities
Rapid deployment of a work care consultant if informal care and work must be combined and that for whatever reason is disturbed
All sorts of forms of education that are aimed at continuing to be in charge of being self-directed as well-informed interlocutor

The development of a suitable and comprehensive range of services from Veurmekaar will take place during the first five years and will continue to extend as needed by subscribers. The service package we describe in this proposal is expressly seen as a 'starter package'. The starting point for the development is the model below.



7.26 The circle of carers, volonteers and patients

In short, this means that Veurmekaar is the pivot in the circle of care recipients, informal carers and volunteers. This pivotal function requires at least a professional front office for intake, contact and advice supported by the smallest possible back office. Furthermore, appropriate services will be deployed and developed at the interface of each of the three parties (care recipients, informal carers and volunteers).

Everybody drives voluntarily

The movement has to be motivating and stimulating to encourage citizens to want to do something for someone else. Research shows that most people are willing to do something for someone else. (Sociaal en Cultureel Planbureau, Den Haag 2015), to be able to do something on condition that they know what they can mean to whom. SIZ Twente is already very knowledgeable in the field of the deployment of care volunteers, so can make use of that enormous knowledge and experience. Voluntary commitment of help can be found, but there are still more groups of people to approach that are keen to help and willing to become volunteers. The search will begin for suitable people within the large group of students in our working area (higher professional education and vocational education) and the large group of people who make use of a benefit and who want to or must provide a counterpart. An internship agency has been set up that arranges the recruitment and deployment of students. These new groups of people can make their contribution to the informal care movement. The SCP has calculated that there are 1.1 million Dutch people without a private network that can be relied upon if there is a limitation in self-care. All the reasons therefore to support those vulnerable citizens with many more volunteers than is currently the case.

There are many ways and forms to shape the use of ‘unused care’: volunteers who work in a hospice, are involved in daytime activities, transport, or just pay attention to each other in a conversation.

Chapter 8: National Acceptance and Implementation of the Model into Dutch Dementia Care Services

8.1: Introduction

As the previous chapters have indicated dissemination and implementation began early in the project. The examples given in chapter 6 have described how each of the 'new roads' developed and activities spread locally and nationally. However, the final step had to be acceptance of the model by the Ministry of Health, Welbeing and Sport. The first formal step in this process, started as a local dissemination conference, but as with other activities during the planning it developed exponentially into a provincial congress with attendees from across the country and representation from the Ministry. The date of the Congress was March 2016, and because of the nature of this study, it was given the title: Family Care and Dementia. The whole emphasis of the day was the role of informal carers in keeping the family together, and enabling the loved one with dementia to remain in the community for as long as possible. Although all the other activities were progressing well, It was seen as essential that a start be made to pull all activities together into one coherent was forward which would support the whole family unit. The issues that had arisen in this study were not new, all the problems and needs of informal carers that were presented and discussed had been recognised and accepted at local, regional and national level for some years.

The problems that had arisen in the implementation of the WMO (2007/2015), and the resulting lack of national progress highlighted the need to change the model of change from the original continuous approach to a the alternative project based model (Herweijer 2020) For this to occur, government approval was necessary, so in the light of the enthusiasm which had greeted the announcement of the congress, I contacted the Ministry of Health, Welbeing and Sport. Having had the royal seal of approval on the young people's element of the project, it was much easier to gain access to members of the two chambers that constitute the government in the Netherlands. The Netherlands has a parliamentary democracy with a directly elected second chamber, comparable to the House of Commons and the 'First Chamber' indirectly elected, equating the House of Lords in the UK.

Meetings were arranged and following discussions about both the youth project, the needs of all members of the living family units, ways of introducing care changes across the country took place. These included recognition that there was an urgent need for activities and projects such as those developed in this project to be linked to services across the country. As a result, the then secretary of State from the Ministry of Health, Welbeing and Sport in the Netherlands, Martin van Rijn, offered to participate in the congress to talk about National Policy for dementia and informal carers. However, as the date approached he had to leave the country to chair an international meeting in Austria, but surprisingly this did not lessen his commitment to what he described as a national issue. He found and offered a solution, he would sent representation to the congress, and would himself make a personal video message to be broadcast during the congress (see screen shot below).

Picture 8.1: Secretary of State Martin van Rijn participating in the congress

The congress had o**ver 450 visitors registered to attend.** These registrations came from a wide range of backgrounds, there were health care professionals, and informal carers, and it is important to note that the latter included partners, siblings, parents, children and friends.   It was seen as essential that the day was not seen as officials 'talking at' attendees, so it was organised with a mix of participatory workshops and more formal presentations providing information. A popular venue was chosen, the conference hall at FC Twente as this was flexible and could easily be set up to include the planned workshops as well as the plenary sessions

Picture 8.2: Delegate at the congress

This format allowed all present to share concerns and explore ways forward, the colleague from the Ministry was briefed to act for the Minister and to present the additional information regarding the government plans for care in the community. The congress concluded with an activity approved by the national government. This was that to help move things forward, and prevent the congress being just another session sharing information. Local governments and organisations who had expressed their intent to work together and improve the care for people with dementia and their carers should publicly confirm their commitment. They were asked to sign a covenant to facilitate shared working. This did not commitment them to specific activities but opened avenues for communication and shared initiatives. It enabled the different organisations to start to work together, firstly by meeting outside the congress, and then by developing share initiatives. This was a first step, organisations who ordinarily had little contact with each other, saw the public commitment and identified from those signing, organisation with whom they could work. With whom they could work this was the start of a movement for partnership working and change that has continued and today is still gaining more and more momentum. However, for national sustained changes in service delivery, the outcomes of this stared working and of this study which was leading the way forward needed to be formalised, and accepted by both local and the national government in The Hague. This took time, but as all the developments were being sustained in January 2019, a series of meetings was arranged with the government, and use of the model to transfer activities into service provision took place. The discussions included a local government official, an alderman responsible for informal care in the municipalities, and a representative from the Ministry of Health, Wellbeing and Sport responsible for informal care in the Netherlands. To confirm progress a series of agreements were signed and photographs taken recording the change in policy that had to accompany the activities if there were to be sustained

Picture 8.3: at the Ministry of Health, Wellbeing and Sport

During the meetings and consultation with the Ministry, the government's plans for informal care were discussed in the coming years. A letter from the Minister of Health, Welfare and Sport to the House of Representatives was written, and included the plans for implementation of the model (See appendix 7) This letter sets out a number of policy objectives that the Dutch government want to work on, the three main actions were:

- Action line 1 Good support and care at home

- Action line 2 Informal care and volunteers in care
- Action line 3 Continue to live independently with a disability

The text of the entire programme can be found via google under the title: Programma Langer thuis. Samen aan de slag. Plan van aanpak 2018-2021 (Programme for individuals to stay longer in their homes: working together. Plan for actions 2018-2021). This rapid acceptance was unexpected, but tremendously exciting, for the first time it offered a permanent change to practice. Formally recognising the importance of the role of the informal care, and the need to support this vital group. It accepted and openly stated for the first time, that informal carers play an indispensable role as they care for and support their loved ones. However, approximately 10% are overburdened to the extent that they may not be able to continue in their self-appointed role. Volunteers who try to support informal carers and their loved ones, particularly when the individual needing care is elderly, also tend to become overburdened, and may have stop the help they offer, if they are left without ongoing and appropriate support. Finally, informal carers and volunteers must be made aware that they are not alone, when help and respite care are needed they should be readily and quickly accessible. Also that there need to be increased co-operation between formal (state) care provision and informal carers.

Discussions continued with a series of meetings reviewing the way forward, and the model developed in this study formed a key element as it fits well with the government wish to move to community led care. By January 2020, the concepts from this study had been accepted and plans were finalised for a concept paper entitled ‘Together stronger for informal caregivers: providing meaningful support for carers in the Netherlands’. *Ministry of Health, Welfare and Sport, 27 January 2020*. This means that the society in the Netherlands has to appreciate carers more and the government provides plans and money to improve the support of the carers.The plan was to begin implementation this spring, but due to the Covid-19 Pandemic this has been postponed until the end of this year.

Although the concept paper was clear, nevertheless, it was agreed that this research project and its findings need to be sensitively introduced in to the Dutch healthcare system to allow for wider acceptance and future sustainability. The overall model has been accepted as appropriate, but it has been decided that the use of a nationally recognised framework that had been successful in the past is gaining acceptance for research findings would be an appropriate mechanism to enable for health practitioners, accept a knowledge translation strategy to implement this research into practice (Grimshaw et al 2012).

After review of possible strategies, it was decided that The PARiHS (Promoting Action on Research Implementation in Health Services) framework would provide a way to introduce the research (Ward et al 2019) (Armstrong et al 2013) . The context is the environment or setting in which the proposed change is to be implemented. The context for introduction of the findings needs to be subdivided into three core elements, an understanding of the prevailing culture, leadership roles and the approach to measurement (evaluation). Other key aspects of context include, the relevance of the research to the population, how the research fits in to organisational structures and procedures that exist, adequate resources for implementation, where resources are appropriately allocated, targeted and managed. Facilitation of the research findings requires careful thought associated with the type of support needed to help professionals change their attitudes, habits, skills, and approach to practice. Documentation needs to explain why the proposed model has been developed, give an overview of what needs to change, and why. To help with this a visual image showing the different components of service provision and the challenge of fitting the 'jigsaw ' of services need to fit together was developed

Figure 8.4: pieces of the puzzle of service provision

The Government provides the policy framework for informal care. The policy documents are used as a starting point. The local overhead is obviously expected to take over the policy documents. The facilitator has a crucial and connecting role. It is the task of the facilitator to connect the parties together in the role of chairman. The facilitator monitors the progress of the work and reports to the client who connects the different test regions and takes care of the resources. The funds are raised by one special fund from the Ministry of VWS together with an amount of money that the regional health care insure, Menzis, contributes.

The care organizations ensure a representation as a delegation within the working group in which all parties participate. In addition to the providers of home care and nursinghome care, the three Twente hospitals and rehabilitation center Roessingh also belong to the care organizations. From there, patients are discharged to the health situation or one nursing home where there is always talk of the use of carers. For each care organization, one working plan is drawn up for the actual schooling of all care staff. The schooling is based on the framework of education from the Ministry of Health, Welfare and Sport and is supported by literature and a development program that is developed from this project. As representatives from the care providers, it would be good to choose very good ANP ers who are already familiar with change management. All interested care providers can participate in the regional project as long as they subscribe to the policy frameworks of VWS.

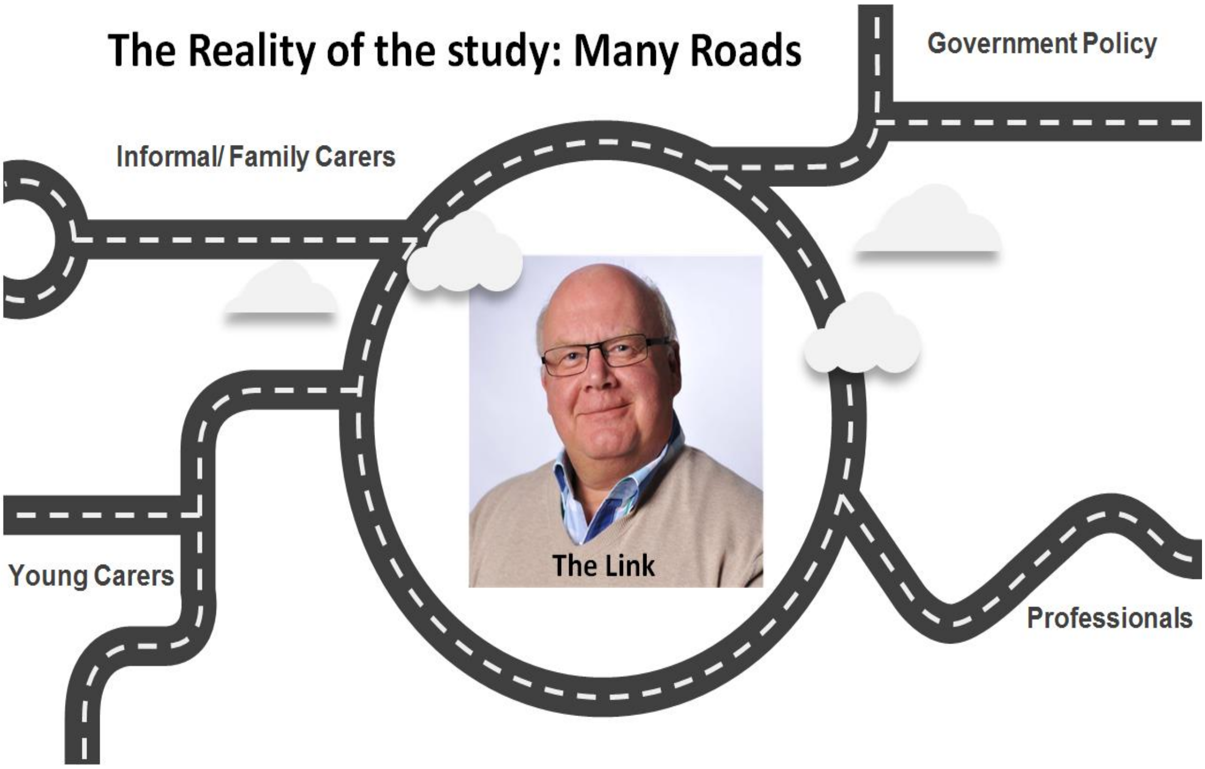
The registration system is an important tool for the implementation of informal care. Existing registration systems are not all aimed at the involvement of informal care within the total care and support process. The registration system will have to be able to comply with a list of requirements to be drawn up in this.

The training institutes have the task of developing a curriculum for all trainers in care, at whatever level. That lesson program is based on the policy principles of the Min VWS. The outcomes of this project are also involved in the development of the curriculum. The input of SIZ Twente as a knowledge institute is very important in this. That teaching program is part of the initial care training! The UT provides research where necessary and is involved in the project in that sense. Each training institute appoints one representative who is part of the working group and takes care of the communication within the own training institute.
The health care insurer Menzis is involved in this regional project as a major stimulator of this development. They facilitate it in two ways:

- They finance the teaching of health care workers and they ensure a recording of the desired results in the contracting of healthcare providers.SIZ Twente is involved as a knowledge center and will play an important role in the training and schooling of students and care staff. They can use their knowledge and make contact with carers who in turn can bring practical situations into the lessons.
- The health care insurer will provide the resources that the care providers need for implementation within the healthcare organizations. The VWS fund provides funding for the development of teaching programs that are regularly included in the training programs by the training institutes. In addition, VWS also finances the facilitator and the required project costs.

The results of the regional Twente pilot are then shared with Min VWS and the national coordination group to be formed. The rollout will follow after the pilot (s) including the Twente pilot have been completed and the results where necessary updated and shared.
The Twente pilot has a lead time of 4 years in which the first year is spent on preparation including the development of a textbook and teaching programs for care staff and students, the second and third year in the implementation of the training and training programs and the last year at the evaluation and reporting. The results of the regional Twente pilot are then shared with Min VWS and the national coordination group to be formed.

The concept of journey had been accepted, and in the light of the train journey developed to support them and 'journey' undertaken by the young people, it was suggested that a diagrammatic representation of the new roads, showing where they fitted into the overall picture, should be made, and with their support, diagram x given below was developed. Initially it was developed without the photograph, but those carers who saw it wanted the person they described as their link and support to be evident.



The interviewees and other participants were happy with this, and at the start of the study, so would I have been

8.2: Government policy

Also, within the government policy the attention for the concept of empowerment increases. Due to the double aging population and the increase in chronic disorders, the number of care demands will increase expansively in the coming decades. A first step is made for policy making and the organization of care for and by the people who are concerned. Extramuralisation and the involvement and appreciation of experiential expertise is put on the political agenda, with the concept of empowerment as a connecting concept.

Chapter 9: reflections

9.1: Introduction

This chapter has been organised into separate sections. It gives a summary of the study in scientific, personal, and professional terms. It turned out to be a journey that I could not have imagined at the beginning, but one that has brought me so much more that I could ever have expected. The starting point, has to be a reflection on the personal reasons for the study, followed by looking back at the aims to assess whether or not these were achieved. The chapter also considers the results, personal reflections of the strengths and limitations of the study (as **a nurse, a manager** and **as the researcher)**, and how the journey progressed and have led to the conclusions and recommendations

As the first chapters indicate, much is known about informal care in our country (de Boer et al 2015). The Social and Cultural Planning Agency (SCP) conducts a survey every two years with carers and care volunteers, but this does not allow for indepth answers, and therefore although numerical data was available there was little data giving detailed information regarding perspectives, wants and needs from the informal carers themselves. Also the focus until recently was on those caring physically for loved ones, with little reference to the impact of caring for someone with dementia. There is little written by informal carers about the challenge of caring for someone with a disease where cognition fails and the personality of their loved one appears to slowly disappear, leaving what some carers described as *'someone else…. not my husband… he has been gone some time…'* Alzheimer Nederland is now very active, carrying out regular surveys in which the role, perception and the need for support of the caregiver are portrayed. However, while these do give useful information, on the whole, the results are given as separate sections, not integrated to described or give insight into the essence of what being and informal care means. Instead there is often a reiteration that the number of people with dementia in our country will increase substantially in the next decades. For years this was a concern, but I needed encouragement from peers and friends to have the confidence to further investigate and explore the topic of informal care and dementia.

9.2: Positionality reviewed

It took years for me to start this study. As a community mental health nurse, throughout my entire working life I have been confronted with the problems of people with dementia. From my first job as a district nurse in which I visited many early stage dementia patients at home, to support them with their general daily life operations, through (as my career developed) to the position of manager in a care organisation which organized the care for vulnerable groups, which includes patients with dementia and their carers. The final career move was my move into the world of health insurance, the level at which the financing of care for people with dementia takes place, where I became a director of a company designed to support for carers, and today I remain involved with the caregivers of people with dementia. This includes those living alone with dementia and those with dementia who live together with an informal caregiver. It was seen as important to recognise that for individuals with dementia living in a nursing home, many of their previous informal carers want to be part of the care system, but felt excluded by the system. They reported feeling more or less denied the possibility to make a meaningful contribution to the total care for their loved one, making the move into care more traumatic.

At the outset of the PhD journey, my experience had resulted in the development of a long held passion and belief in the necessity for the improvement of the position of the informal carers and in their recognition as a core component in patient care. To that end I had spent many of my years in practice as a teacher of healthcare professionals, initially on a one to one basis, as a community nurse teaching and training students. As my qualifications and expertise grew in this area, I gradually moved into teaching in the training institutions, and into management training. From the outset, because of the approach chosen, I had to look at myself, reflecting on my role and responsibilities

When I started nursing, I saw myself as the professional nurse, so I took care of the person with dementia being, I thought, the most important person in the care process. I thought in those early days that I was taking over the care from the informal caregiver. That was the way we were trained in those days. However, nothing was further from the truth: after my departure, there was still so much care for the informal caregiver to provide for their loved one with dementia. In reality, the major part of the care was carried out by the informal caregiver, but at that time, if I am honest, little attention was paid to this crucial group of people, and there was no way that that we would involve the caregiver in the care plans, really engage with them, by giving them a voice and a decision-making power.

Once I became a manager, speaking to many carers, I found that in many cases they had a difficult time because they were not seen as valuable partners in care. In my role as a manager, I felt that improvements had to be made in support of those carers and in their position. My passion to help was there, and I did my best in my organisation, but it was on a relatively small scale. However, in my contacts with Professor Dr Joy Notter I slowly became convinced that I should substantiate this scientifically. She convinced me of the usefulness and necessity of this study. As a manager I had my hands full with the daily work in supporting carers by offering them support forms. However, as I had been arguing for change for years, I had to accept that I knew this would not be enough and so I decided to start the study. I knew even then that I would always be the nurse who wanted to provide immediate help and the manager who immediately wanted to organise the support for the carers.

At the same time another change meant that I could not continue to ignore the need for change. The tremendous increase in the number of people with dementia in our country has put more and more pressure on care services, and yet there has been little additional funding. The result is that more and more expectations have been placed on informal carers, and their role is of increasing importance in the maintenance of care. Without them their loved ones would be in permanent full time care. Not surprisingly, the role of the carers is now receiving increasing attention in the Netherlands, but it seemed to me that they still did not receive the respect and recognition that they needed. This, even though they were needed to deliver a big part of the total care that is provided where necessary by care volunteers and professionals. Slowly it was getting better for the carers because they can claim an identified role in care, but really this was because the steadily increasing costs of the total care system in the Netherlands meant that these informal and unpaid carers were essential if the health care system were not to be overwhelmed.

The final recognition that this project had to be a first step and that other fields of care also needed learn to the take more notice and offer respect to the informal carers. In general care, it seems that really nothing has changed regarding involving informal carers in care planning as my own experience in 2019 confirmed.

9.3: Personal experience

Bad message

In January 2019, I accompanied Mother during an appointment to the oncologist. We received the message that she had one abdominal tumour and probably two, Mother, on her way to her 94th birthday, said on our return that she did not want any treatment and just wanted to live with dignity and without too much trouble to the end of her life.

She wanted to continue living at home and with us, her children and grandchildren until the end would be there. *"I had a good life, and I have to die of something,"* was her statement for which I had a lot of respect because of the seriousness of thje decision, and because in my nursing I had seen the results of intensive treatment on much older people.

Informal care

I was - and have been - her caregiver for years and luckily was able to ensure that she still lived independently near me. My mother was an upright independent women, we lived in the same block of flats, and I was her informal carer, for as much as she would let me do!!

All her other children and grandchildren live at least 100 km away. I am familiar with the phenomenon of informal care and all the positive and negative experiences and feelings that (may and frequently do) accompany it.

Mother’s Care

What care would mother need at home and what help would be given to support me as her caregiver? As a start I wanted personal care daily and household help in addition to a personal alarm. So I started quickly to arrange it. If you don't know how the health care system works in our country, the search starts here! The first telephone call to the municipality did not yield much at all, apart from the urgent message to request a ‘Wet Langdurige Zorg’ indication as soon as possible. To which my reply was "We don't want that because Mother wants to live and die at home." However, a second telephone call with the concrete demand for household help ended successfully: we could immediately deploy household help. Just look for a good provider and that part was arranged. Then I called home care for the deployment of personal care and the second provider immediately had a place: they could take her on their books the same day and the care was started. A care file was set up on the table and on the first page my name: Caregiver with address and telephone number. Sheet 1 and at the front of the file!

The Hospice

One afternoon after a few months of care, I went to see my Mother. Mother told me that during in the afternoon she had had an unexpected visit from two people from home care. "*They were suddenly sitting on the living room couch*," she said. The two professionals told my mother that the care became quite difficult and hard without indicating for whom the care became hard - and perhaps too hard. Mother was advised to orient herself to move into care in a hospice. She was shocked by this.

Mixed feelings

I was stunned! Why I was not involved as a caregiver in the composition of the care plan and the option of admission to a hospice? We, as a family have not been contacted or considered, no-one has looked at our efforts in caring at all in any way. No one has spoken to us, not even to ask our idea about the final stage of mother's life and our role within it. Why would they! What right do they have to dictate to her, on her own without me there? Obviously, they couldn’t find me right? After all, my name and telephone number are only on page 1 of the healthcare file?

Mother died in the summer of 2019, as she wished.

I have included this because it occurred during my study, and after I had initiated all the activities that were designed to support informal carers. It felt like a slap in the face, I really understood the anger, resentment and pure frustration that the informal carers had felt when they were ignored, with plans made for their loved one without consent or discussion. It showed that the informal carer, myself, was still not seen as a logical part of the total care for the patient, my mother. It showed that the carer still has no role in the care plan and no power to develop the best care for my loved one, and the most adequate support for me as a carer. And all this despite the fact that government documentation states in all forms that every professional care provider uses, that the informal carer should always be included in the care for the patient.

This just reinforced my decision to complete the study and to get the results accepted at the highest level, so that this would not happen to others in my position. It also convinced me that there was a definite need to educate the professionals, they also needed a degree of empowerment. They must learn to deal with the informal carer, to take them seriously and recognize their role and position. It seemed that this study had one clearly emerging theme that of empowerment, seeking for ways to empower the informal carer, and to empower the professional!

9.4: The three roles

Looking at the study as a whole, considering what worked and what didn’t, I have again looked at the three roles I needed to integrate. Overall the internal dilemmas that arose from having the three differing functions, were not easy to resolve. At every step I could feel the different ‘me’s trying to take the lead

The nurse

This turned out to be a great experience for the nurse, providing immediate solutions to problems and questions and needs that were introduced from the interviews. However, it was also a time of frustration as at all times I just wanted to be the nurse who could help resolve problems. It proved to be the final break from the old regime where the professional was paramount, and 'took care of' the patient. I knew at the start that I wanted the whole family unit included, and to increase the care and support for the informal carer. I now find that I have reached the place where I see the patient and informal carer as entwined elements of an integrated family unit. This will change my nursing for ever

The manager

For the manager, as the project progressed the work load grew exponentially, my hands were full with starting up new activities and projects. The challenge was finding ways to respond ever emerging needs and wants that the study revealed. The nurse had to be prevented from running blindly into new activities just to solve one set of concerns. As I could see why individual actions would help in the short term it was hard to exercise restraint while I sought for the finances necessary to start new initiatives, and developed the plans needed to enable me to identify staff who could be involved, or employed to carry out the implementation. However, it showed me as a manager, just how far apart the services and the users were, and the magnitude of change needed to empower the users and in the increasingly constrained financial system maintain and enhance services. I needed to seek for ways to widen the influence of the project findings, and while that has been possible, it has been an ongoing challenge to always me knocking on doors and chasing after support from key stakeholders. I would not have missed any of it that as a manager am thrilled at what has been achieved, but I have to admit, it has been at the expense of the speed with which the study could be completed.

The researcher:

This study is a clear example of findings really demonstrating the lived experience. Early on in data collection it was completely clear to me that the care for people with dementia is largely carried out by the caregiver, with from the carers perspective minimal input from care services. It was evident that the informal caregiver was engaged in an ongoing battle to indicate what he or she can do, and wants to do, as well as identifying where additional professional care is required. It was also a shock as it revealed that the research had to achieve much more that I had originally planned. In

my naivety, I had envisaged collecting data, analysing it and then using the results t improve practice. Instead I had launched something that had a life of its own, that attracted increasing national interest, and beyond my dreams ultimately involving the government.
The research was constantly delayed by my two other roles, and while this was appropriate, as a researcher it was intensely frustrating. To be really effective it needed to be finished and handed over. The interest by the government placed me in a dilemma, I handed over my findings to date and was stunned when they came back with a concept for changed based on my research. I now realise just how powerful research carried out at the right time can be, also the impact of social media. It cannot be denied that the interest was increased at national levels by the media impact.

As the study unfolded, I became more and more enthusiastic about the fact that I had to fully surrender to the results of each part in order to take the next step. And that was not so easy for me. Leaving the direction to the results of my study meant leaving the direction to what the informal caregivers said. So in fact leave the control of the caregivers. I had not fully understood when I was told the data dictates the findings and the study direction. I had accepted the statement, but had not fully realised what it actually meant, and how hard it would be to accept the findings in their entirety and not seek for what I wanted to find. I have learned so much as a researcher, and that has included looking at myself as well as learning the methods and techniques of research. It was the correct decision to look at my position as the researcher and identify the three key components, but I did not know the extent to which I would end up reconciling the different roles. However, it was helpful as I tried to work out what I was doing to be able to rationalise the challenges and work through them.

9.5: Summary

So this study has also been a journey for myself, in many ways it has paralleled the journey of the informal carers. Just as the participant who said ‘You don't really know exactly what you're getting into, so you don't know what to bring with you’, I really did not know what would happen next, and had not expected. It turned into something that swept me along with it, and I wouldn’t have missed a single moment, but I still don’t know the final destination and I still find I don’t have the correct luggage with me for me it was also the case that I did not always have the necessary luggage with me. I am overwhelmed by the achievements that have occurred as the project has progressed, but realise that without the project none of it would have happened. Oh, some activities may have developed, but the move from a community nurse who had become a director of a care organisation, to a nationally recognised and honoured figure, whose work will change dementia care remains hard to comprehend. In many ways I still cannot believe it has happened, but I am determined to make sure that this time the plans for change will not be lost due to lack of concrete guidelines leading to procrastination and little long term action.

I cannot ignore the long term personal changes that have occurred. From being an executive in one organisation, with an understood management role, I have become a national figure, and leader in the field of dementia care, in some ways it can be compared to becoming a celebrity in health. I am now recognised wherever I go, and contacted on a regular basis by local and national media. This has taken time to adjust to, at first I felt uncomfortabl being described as ‘an expert’, but over time I have become used to it. I now realise that while in my own eyes my knowledge is limited, for informal carers I have the expertise and knowledge they need, with my many years of experience enabling me to find my way round the healthcare systems and guide people along their journey. As recognition increased, I was concerned that it might affect this project, but fortunately the ‘celebrity status’ only occurred as the progressed, and after all data had been collected. Consequently it did not affect participants’ willingness to participate, although many have sent feedback saying how pleased they are that the project was carried out, and how proud they are to have been part of such a project.

The project activities I have led, as well as raising my professional profile, certainly have helped to increase recognition and awareness of the plight of this essential group of informal carers and have led to discussions with professionals, politicians and the lay public of the changes proposed. Government acceptable of the model and their willingness to implement it in total, was easier than expected, but on reflection has probably been influenced by the expert status I have been accorded. Regarding the media, having found an identifiable ‘expert’ health care professional to contact, the regularity of contact from newspapers, radio and TV seems to indicate that they are now willing to publicly raise queries. Overall, I feel humbled by the national position I new find myself in but it is essential for me to accept that but while this does keep the issue on the public agenda, it does not in itself change practice.

The final challenge for me is that implementing a project on a national scale is much harder than just completing a project on a local level. The changes it demands are immense, the collaboration between professionals and carers has to be radically changed and reorganised. For the informal carers to be given the lead in the total care for a loved one, the cooperation, the interaction between formal and informal care will have to be completely different. The project showed a major paradigm shift was needed. The way forward needed thorough rethinking! Although the path for the project appears clear, for me, my position is so radically different, and I still do not know where it will all end, but I am just so profoundly thankful I did undertake the project, and as a researcher I will follow where it leads me.

Chapter 10 Critique, conclusions and recommendations

10.1: Introduction

This chapter focuses on a critique, conclusions and recommendations, of the study as a whole. It has been divided into sections, with the critique interwoven into each section.
Three aims have been formulated for this study:

- To gain insight into the motives for caring, and the needs and wishes of (family) carers who are caring for a loved one with dementia
- To develop a conceptual framework and model that would accept that the family unit and not just the individual needed to be the focus for care.
- To make recommendations for policy and practice

Using these overall aims, two questions were formulated:

- What are the lived experiences of carers who are caring for a loved one with dementia?
- What do (key) carers of a loved one with dementia need in terms of services and support to be able to stay as key carers for as long as they wish to?

Overall, these aims and questions were appropriate and addressing them has led to the actions and activities presented. The previous chapters clearly illustrate that each of the aims, and the two questions have been addressed through the collection and analysis of indepth of descriptions of the lives lived by informal carers and their families. A wealth of rich and indepth material has been collected, collated and analysed, adding to the current knowedge of, and insight into the lives of informal carers and their families. This was then used to address the second aim, and here the results have been exceeded. The aim was to develop a conceptual framework and model to improve care services and support for the family unit. In the event two models were developed which where integrated form the conceptual framework which will now be the basis for a paradigm shift in care. The third aim was to make recommendations for policy and practice. However, at no time had it been envisaged that by the time the study was finished they would have been seen by government, accepted and be in the process of being piloted across the country. Implementation meetings start in September 2020.

There are also some general points that need to be considered. The research paradigm chosen was interpretivist, and as the focus was on developing a model and conceptual framework for the family unit, the philosphy that describes the famly as a 'living unit of interacting personalities', symbolic interactionism seemed the most approprariate. In this approach roles are established with the family based on expectations and behavioural responses (LaRossa & Reitzes 1993, Carter and Fuller 2015). For this study it meant that the family unit (family) with one member with dementia meant continually changing roles, and adaptations to the ever changing family and social situation and care needed. This study clearly showed the participants had had to change and adapt as their family circumstanses changed as the diesease trajectory progressed. The challenge was that as time progressed, these units appeared to have turned inwards, with the main informal carer finding less and less time to be an individual and more and more time becoming a carer. A way had to be found to help them rejoin the live they had shared with their peers, and the model developed for the family unit grew from the analysis and interpretation of data that woould not have been possible if an approach that did not include recognition of the symbols important to individuals and they way they use them to love their lives had been used.

10.2: The approach used

The choice of an interpretivist approach with its ability to utilise what was revealed to influence the way the study moved forward added greatly to the insights gained. However, it has to be noted, that this was not an easy approach for me as a community mental health nurse. I was used to providing care based on my experiences and expertise, not standing back and letting the lived descriptions from the participants, set the scene, indicate and guide the way forward. I had to learn to follow where they led, an unusual, but incredibly rewarding experience, in a way, as they willingly shared their experiences with me, I had to learn how they used their own processes and symbols, responding to develop tailor made activities for the different groups. I have learned to appreciate the philosphical appraoch I used, but realise that for me the journey of learning has really only just begun, and that I have only just scratched the surface of the theoretical concepts underpinning symbolic interactionism. Nevertheless, it has given me a much deeper insight into how individuals and families interact with each other, their surroundings, as well as their own definitions of how they relate to each other and the symbols of modern life. It highlighted the differences between health care professionals and the families and communities they are there to serve. It made me aware of the need for a paradigm shift in thinking to to give back to the families the independence and power of decision making that they had lost as a result of the onset of dementia. This led to the emerging themes illustrating the need for the empowerment and will continue to govern the way I look at the family unit,

Grounded theory, the method linked to and emerging from symbolic interactionism was the most appropriate method to use for this study. The iterative processes which are a core component of grounded theory (Charmaz 2014) were essential to the generation of emerging themes and the use of the final data sets. From the start of data collection, the concurrent processes facilitated recognition of new and additional issues that were of importance to the participants. Originally planned with a small set of topics for discussion, the new issues that repeatedly emerged, showed from the beginning that there was an immense gap between community service provision and the support the informal carers actually needed and wanted. These insights had to be incorporated into the discussions, and then raised with all later interviews and/or focus groups. The willingness of all participants to share their personal experiences and to work with the researcher was overwhelming. This strengthened and enhanced the study as a whole, with the individual and group responses impacting on the study at all stages, leading to the whole range of activities that were set up and the development of the four new roads. This study with its rich and detailed information was the first in-depth study to focus on the whole region of Twente. The findings were so consistent and detailed, that they provided an invaluable source for the development of both the family empowerment model and the 8 step change model. Putting the two together has delivered a conceptual; framework based on two models that that has, and will change the approach to support and help for informal carers' across the Netherlands.

10.3: conclusions

The paradigm shift in thinking that came from the iterative processes used in the study had major implications for all aspects of the proposed approach to care provision. It was evident that it would not be enough to merely increase the support offered, instead there needed to be a complete change of attitude, for the first time professionals had to learn to abdicate responsibility, accepting that the power should be with the informal carers. Their role needs to be recognised and they need to be given respect for the crucial position that they have on the whole, undertaken voluntarily. The professionals have to accept, as I have done, that they are not the most important care providers, but that the informal carer is the one who gives the majority of the care all day every day. For effective support the informal carer needs to be encouraged to identify for themselves what they need, but for that they need to have their personal experience respected, self-esteem and the ability to view their personal situation, both as a carer, and as an individual. For that they need to be empowered, thus, this became and still is, the key concept.

The study also demonstrated clearly that different groups of informal carers have different needs, with the lack of accessible community support proving to have been of obvious importance. There needed to be recognition of the very different roles, perceptions and needs of the different age groups, it was a shock to realise that while few carers reported having been seen as key to the care of the individual with dementia, for some groups, such as young caers there had been and almost total lack of help and support. Another disapointment was the insufficient knowledge of the phenomenon of dementia reported by informal caers, and the difficulties in accessing knowledge that they described. The reulting additional activities designed to address these issues (as illustrated in previous chapters), led to local and ongoing national interest. This in turn led to political interest and requests to work with local, regional and national policy makers. This took time as the framework had to be adapted to fit within the wider organizational and political factors of care provision at all levels. For this I had to change my roles adding in facilitator and link between theory and practice. I needed to link with planners and service managers discussing with them ways to implement the framework, for all involved from individuals, nurses, team leaders programme directors and managers, supervisors, health promotion officers, community development workers through to government ministers. For this, a structure was necessary, based on the policy plans as indicated in the WMO (2007) from the Ministry of Health, Welfare and Sport. These were by now over a decade old and needed to be updated to meet the changed context of health and social care that exist today through a new knowledge, translation and sustainability structure. The national acceptance of the findings of this study have continued to grow, and as discussion with ministerial representative continued, it gradually became clear that events that I hadn’t even dreamed of have led to polices to make permanent changes in care provsion, which it is hoped will lead to implementation of the original aims of the WMO (2007).

Summarising the findings, there are a few key points that policy makers, service providers and health care works in general need to remember. Firstly, there are no two identical caring situations, therfore, the traditional ‘ one size fits all’ approach inevitably fails to meet the needs of informal carers, leading to loss of confidence in services and ultimately damaging thenformal carer who ends up trying to cope unaided. Currently, there is evidence that only 20% of informal carers actively ask for help and support, with the majority only seeking support, when the burden of caring has already become too much. (SCP 2015). This means that by far the majority of carers carrying out the total care themselves and run the risk of burn out, and having to stop caring (de Boer et al 2015).

Carers are not sufficiently aware of the impact of caring on their own health and wellbeing, they have trouble looking for- and finding adequate accpetable and accessible forms of support. They need help and guidance for themselves and their families from the professionals, but also from those within the community who have lived similar experiences. Carers in this study wanted to take much better care of themselves, but did not know where or how to start. They have very limited time, and lack of success in the past has led to resignation and a reluctance to “waste *my time” again*. Support for carers can come from different sources within, and outside the immediate family, from the community itself, or it may be initiated by professionals such as home care nurses or social workers working for the municipalities.

Empowerment for this group needs to take account of their vulnerabilities and anxieties, accepting that it will take time and care for them to gain the confidence to start to take the steps to indpendence for themselves. Then too, it has to be remembered that in the early stages of caring, informal carers are optimistic about the idea of caring for their loved one for as long as is needed. Retrospectively they indicate that they should have looked after themselves much better from the start and should have called for help much earlier.

Also, there is a great need for community information and community empowerment. The Dutch citizens must be well informed about the proposed paradigm shift that goes hand in hand with the implementation of the new health care system: from maximum care by the government to self-care and informal care first and only where necessary, the use of professional care. Although this has been planned, it is such a change from the traditional approach, whereby the professional holds the power, and the informal carer has felt powerless to change things that it is likely to be some time before the situation changes and the informal carer feels able to seek out professional guidance.

Caring for a loved one is an important and very valuable part of our society. To be able to care well and for as long as possible, information must be available on a range of issues. To date accessing appropriate information has been difficult, and, it was a shock to find how few carers actually knew which type of dementia their loved one, or the disese trajectory. in addition, most reported being given *'nothing.... no information about how looking after xxx* [partner] *would affect me'*, consequently for most the slow loss of independence and of their own life interests had '*crept up'* on them with most only realising the extent of their loss when they were well into the role of carer, and had already given up most of not all of their own activities. The lack of guidance regarding support compounded the situation, as they did not know to whom to turn they tended to struggle on alone. This is not new, it has been known for years, and included in government reports (see chapter 2) but in reality the positive statements made reports proved to be only rhetoric, rather that focused information that they could use to access support based in their location. The differences reported across regions needs to be addressed, with standard services services offered across the country, support should not be based on a lottery linked to their address.

The informal carers wanted information that was easily accessible and user friendly, with clear sections and guidance on what can be found where, they were tired of having *to 'search endlessly'* for themselves through a '*huge amount'* of information spread across different websites, Interestingly, although professionals may express doubts about whether or not carers want to know what the future will look like, this study found that almost unanimously they wanted to know as much as possible. It was not accpetable for carer after carer to report that they '*would have made other choices* 'if they had known what lay ahead. Not should the majority had had to feel '*so alone'*. For a carer where there is an increasing difficulty in meanngful conversation, it is a difficult for them to know what their loved one really thinks about them, whether they are '*doing it* [care] *right'* and what the care means to them.

Informal carers, want to be seen as equal partners in care and care planning, openly stating that they feel the need for appreciation and recognition without having to ask for it. That for most, the lack or recognition and support had led to them feeling that they were of little value, was distressing to hear. The interviews often revealed a loss of self esteem, and few signs of self worth. They needed appreciation and recognition to give them the reassurance that they were caring well for their loved one, without it they experienced self doubt, and instead of feeling they were the mainstay of caring they felt like unacknowledged adjuncts to the professionals. The professionals often tend to take the lead from the moment they are consulted, with the result that the informal carers staed they felt like '*an outsider'* who could be ignored, over-ruled and who had little right to play a role in the care of their loved one, let alone lead it. Unfortunately, the interviews also revealed that the informal carers saw professional care as '*better'* than the care they themselves provided. Informal care has traditionally been seen as an 'add on' to professional services rather then the 'capstone' of care.

In addition to the main informal carer, a series of others may be involved in caring, these can include young people, who want to become, or have become young involved in the care. The emotional burden on the young carers is well documented, but little attention has been paid to the young people themselves. The result is, that to their own dismay, they are often excluded by their families trying to protect them, and not wanting to see them burdened with a caring role. This may in part be because they are aware of the impact caring has had on their lives and they do not want to see a child similarly burdened. While this is praiseworthy, it is an adult perspective, not that of the young person, which actually leads to a different but equally distressing burden for the young person. They see themselves as being involved as a member of the household and want to *'join in'* and help their families care for their loved one. Exclusion then brings with it a heavy emotional pressure which they tend to carry alone. It is precisely this exclusion that has large and often negative consequences for them causing problems and feelings of rejection. Professionals need stop to reflect on how they approach young people. I had always considered myself to be inclusive, but as illustrated earlier, found to my own horror that I too tended to focus on the adult members.

What this project has taught me is that all family unit members have to be considered, children must be listened to, and ways found, to enable them to play a part, however limited in the care provided within a household. Children are no different to their elders in that they too become from the start very focused on the needs of their loved one, looking too little, too late to their own needs. They may well be unaware of the impact caring has on their own health, their personal development and their emotional needs. Raising awareness, and empowering and emancipating young carers, is not easy, it takes time and effort, and it is essential that their place in the family unit is not permanently damaged. These young carers need help in the formulation of their support needs, they need to consider all aspects of their wellbeing including mental health, and the real challenge is on finding ways to help them stay within their age- and development specific social network. The new road for young people, was developed with them and for them with the help of specialist youth workers and organisations focusing only on young people. Its success was precisely because the activities and ways to move forward were not dictated by adults, but developed in partnership, allowing the young people to gradually share their concerns and be supported by a ‘buddy’ that they could accept and trust. Watching these young people grow and develop was a salutary learning experience for all of us from the most junior member to the King himself.

At the start of the project, I knew that respite care was limited and that it took time to access, what the project showed me was the human misery caused when a carer at the end of their tether could not find a way for just a short break. There are various types, but it seemd to the carers in this project that respite care was like a carrot just dangled out of reach, often only being accessed when they were too tired to take advantage of the break they were offered. For some it meant that they were just *‘coming round’* when the respite stopped, so on paper they had had support and time for themselves, but all they saw was time to sleep, not time to do anything with their own friends or other family members. For some carers, unless the respite care was in a place familiar to the loved one with dementia, the distress and anxiety exhibited by their loved one was too much. Particularly as for this group settling back into their own home could prove equally traumatic. Alternatives are needed whereby the individual with dementia remains in their own home, or a familiar place, cared for by professionals, giving the informal carer time for themself, while at the same time they know their loved one is safe and secure. However it is provided, its function is to temporarily relieve the carer, enabling them to rest, recuperate and sustain the role they have adopted. Thus, this area of care needs to grow rapidly, with care planners using all possible options to develop innovative strategies for respite care to find solutions that meet the needs of this growing and complex group. The rationale for respite care, not the traditional format it usually takes (eg admission to a nursing home) needs to be at the forefront of planning to future proof its effectiveness for this important but vulnerable group.

10.4: Summary, Unexpected recognition

This project has achieved so much more that was hoped when i first set out on the journey. It is still hard to accept that what started out as a PhD designed to improve the services and support for informal carers, is now a pivotal part of the Dutch government's policy for implementing care in the community. On a personal level, once the decision had to been made to adopt my work, I was summoned to a meeting at the town hall. It was full of professionals,and people linked to me. To my stunned amazement I realised that I was the guest of honour, and that the mayor, had been asked to lead a ceremony in which he acted as repesentative of the King, and carried out a ceremony which was the equivalent to the ceremony of knighting citizens carried out by the Queen in the UK. A brief history of the reason for the ceremony was presented to the audience, including that the models and framework developed are going to be implemented on a national scale over the next five years. The government is confident that it will lead to a better and more effective working method to support informal carers as they care for their loved ones with dementia in the Netherlands. At that point the Mayor formally stated that he was empowered by the King of the Netherlands to award me the title of knight of the House of Orange: Rider in de Orde van Oranje Nassau.

10.1: Picture: Pinning on the medal

10.2: the medal and sash

This was an unlooked for award, beyond my wildest dreams, to be made a knight of the realm for completing this study, felt at the time, and still does feel unreal. It was the final realisation that there was no going back. I was and am committed to acting for the government for the next five years, as we work to implement the study. As this study is completing (August/September 2020), there has been an announcement that a decision has been made not to just use Twente to pilot the new approach, but to fund similar projects across the country for the same timespan. The evaluations from all these projects will be used to refine and where necesaary modify national policy for service delivery. At the same time as making this announcement, two government papers have been released (‘City Deal’ and ‘Integrale samenwerking’, integral cooperation) giving great clarity as to how the implmentation will take place, and how it is being translated to other vulnerable groups. It is hard to predict now how far things will progress, but it is safe to state that care provision for informal carers of individuals with dementia will change beyond recognition over the next five years. For the first time, moves are being made to hand back the responsibility and decision making to the informal carer, enabling them to make the key decisions in partnership with professionals. They are being asked to move from passive anger and resentment to acceptance, active participation and control over their own and their loved ones care. The changes planned have arisen from a major paradigm shift, for all involved in the care of those with dementia, whatever their role, professional or user, the work of care will be different. For the informal carers, who have faced months and years of struggle that it will take some adjustng to, and I will be with them every step of the way.

10.5: Recommendations as the journey continues

10.5.1: Recommandations for Policy

Currently the national policies for the care of those with dementia have been couched in general terms resulting in regions autonomously interpreting the guidelines the underpin national provision. The little harmonization of provision across the country as a whole has led to a regional lottery of support service. Thus, the facilities for people with dementia and their informal carers vary with limited parity of provision, leaving some family units disadvantaged.

- **National policy guidelines, need to be developed with standardised support services across the country**
- **Policies and guidelines designed to improve the support available for informal carers of individuals with dementia must include strategies for empowerment**

10.5.2: Recommandations for Service provision

The paradigm shift in thinking that accompanies the new approach will change the hierarchy of power between professionals and informal carers. If as planned, the informal carers are to take back control for the care and support services they receive they will need to gain the confidence and self assurance to accept their new position.

- **Carers must be seen as (the most) important partners in care provision**

- **Carers must be empowered to accept the changed hierarchy of responsibility for care**

- **Care plans for the living family unit must be developed at the point of diagnosis, which should be monitored and adjusted as needed. These must include separate plans for each member of the family unit**

- **Support services must be customised to meet the specific needs of each family unit**

- **Increased, improved and a wider range of reliable respite care possibility's should be developed**

10.5.3: Empowerment of carers:

The paradigm shift in care will impact on all informal carers.

- **There needs to be recognition of the different needs of young carers. If they are to be supported as they move through childhood and adolescence, tailor made support services developed**

- **Informal carers should be offered programmes such as 'the art of caring and letting go' (De kunst van het zorgen en loslaten) which have proven to be effective tools in empowerment of informal carers**

10.5.4: Empowerment of the professionals:

Professionals should always, in any situation be aware of the position of the carer(s) and develop not only care plans for the patient but also a support arrangement for the carer(s). They need to be able to relate and interact with the whole family unit, from the point of diagnosis through all stages of the disease trajectory.

- **Health care professionals must receive education and training on the role and function of informal care for patients with dementia**

- **Initial and post-registration education programmes in health and social care must be evidence based, uitilising findings from the full spectrum of research, with findings from qualitative studies such as this one providing context specific indepth insights into the lived experience of service provision**.

10.5.5: Information

National information campaigns need to be developed in the Netherlands in which the general public is given access to information defining informal care as a phenomenon, and clarifying the position of informal carers as an integral conponent in the health care system. because the health care system is more civilized in a regional context, information must be coordinated and coordinated at national level, but implemented at regional level

- **An adequate information programme are national, regional and local level, should be developed and made available for all informal carers from the start of the caring process.**

10.5.6: Empowerment of the community

Community's should be more aware of their possibility's to support all the carers in their own community. Society and community's should be prepared for the big growth of people with dementia and should be aware of the position of carers.

- **There need to be community based programmes developed to inform the community of the changes in care provision, and the role they are expected to adopt.**
- **Guidance and resources needs to be developed to support community based voluntary groups as the begin to take up their new support roles in the field of dementia**

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Appendices

Appendix 1 Initial set of open ended questions and themes for the individual interviews

Themes	Questions
Introducing the research	Characteristics of the participant: - age and gender - for who cared for - caring time in a week - how long - where: at home or outside
Seeking a nice and safe place for the interview	
Telling the story of caring from the start	
Motivations	
Experiences	
Support given	
Support missed	
Wishes for themself	
Wishes for others	
Anything that is or could be important to tell	
Possibility's for after care or contact when wished	

Appendix 2 Program Focus Group meetings

Inviting 10 caregivers of a person with dementia, a loved one
Parlor arrange with coffee / tea, sweets
1 secretary
Voice recorder
Pieces of paper and pencils
Suitcase
Sticky Notes
Tables and chairs in semicircle
Reception with coffee / tea

	Who:	Time:
Welcome and introduction to the topic, research, importance of focus group for the study.		10 min.
Quote: ‘the care for someone with dementia is like a journey, I know I am going to make a trip but I don’t know where I am going to and for that, I don’t know what to take with me in my suitcase’		
Round one:		
Introduction of participants: motivation and experiences		25min.
Round two:		
The need for support		25 min.
Open question, think of pairs per 5 minutes, by twos report Forum group		
Break		10 min.
Round 3		
Wishes for myself as carer		20 min.
Wishes for other carers		20 min

Closing and acknowledgments	10 min.
Total	120 minutes

Appendix 3:

Findings in interviews put in dimension of Hubers Postive Health

Motivation to care	**Personal impact**	**Head dimensions**	**Aspects**
It feels good to care	I get enough satisfaction from caring	Spritual and existential dimension Mental functions and experience Quality of life Social participation	Meaningfullness Goals and ideals Selfesteen and selfrespect Balance
It want to care as long as possible	I just don't care enough	Spritual and existential dimension Quality of	Ideals and goals Acceptance Wellbeing
This is the way it should be	I should do more: feel guilty	Spritual and existential dimension Mental functions and experience Quality of life Social participation	Acceptance Balance Meaningfullness Feeling well Veerkracht Resilience Zelfrespect
You just do it	I feel ignorance	Spritual and existential dimension	Acceptatance Resilience Meaningfullness

		Mental functions and experience Quality of life Social participation	Meaningful relations Selfrespect
I feel sorry for my loved one	I feel powerless	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Meaningfullness Well being Balance
I love the one I care for	It gives me no satisfaction at all	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Meaningfulness Energy Meaningful relations Enjoy
It makes me happy	I have to fight constantly with the professional care givers	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Meaningfullness Meaningful relations Social and communicative skills Social awareness Working ability

My parents cared for me, now I care for them	To handle the situation feels like a heavy burden	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Cognitive functioning Resilience Quality of life Wellbeing
	I feel constant pressure : I have to be there 24 hours a day and 7 days a week	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Cognitive functioning Resilience Quality of life Wellbeing
	Its very heavy	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Resilience Quality of life Wellbeing Cognitive functioning
	Roles in our relation are turned around	Body functions Spiritual and existential dimension Mental functions and experience Quality of life	Energy Acceptance Resilience Quality of life Wellbeing Cognitive functioning

		Social participation	
	I have to be there always, no change on relief	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Resilience Quality of life Wellbeing Cognitive functioning
	I feel I have to look after myself better and that feels selfish	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Resilience Quality of life Wellbeing Cognitive functioning
On a scale from 1-10 give myself a 7,8	I did not understand his behaviour so I was very mad at my husband	Body functions Spiritual and existential dimension Mental functions and experience Quality of life Social participation	Energy Acceptance Resilience Quality of life Wellbeing Cognitive functioning

Support

Support needed Mental health	**Support needed Practical**	**Support needed Technical**			
The professional gives me the support I need	The professional gives me the support I need	I can't imagine how technics can help me			
I get help from my family, relatives	I get help from my family, relatives	I don't need technical support			
I get the mental support from relatives I get no support from relatives	I get support from professionals	I can find information in the internet			
I have contact with other care givers and that helps	I need more help but can't afford it	I can e mail with other care givers			
I get support from informal care SIZ Twente		I'm not enough into technical support: in don't understand it			
I get support from a case manager dementia	Please give me more help				
I get help from my GP	I get no help at all from my GP. He did not believe me as I told him my				

	husband was behaving strange.				
I need mental support!	I need practical support				
I did not want to disturb my children with my own worries and burden. They can not handle it and I want tom protect them					
I was protected by my mom but I had many emotional problems with the fact that I was not part of the caring but part of the concequences of caring by my mom.					

Wishes

Wishes for me as carer	**Wishes for other carers**		
Information is needed!	Take care of yourself also!		
Better contact with professionals	Take time off		
Better and direct communication with professionals	Get yourself a sparing partner to talk to		
Better cooperation between professionals	Get yourself information!		

I want to know what I can expect	Be aware of the situation and your own position		
I want to meet other carers in the same situation	Be always honest to yourself and your surrounding		
	Share with your family members		

Appendix 4

important conditions are described for good dementia care are:

1	Carefully dealing with patients and their loved ones means that you always take into account the stage of dementia. It is very important and this requires a knowledge of the different stages in dementia. The person with dementia and the carer is being addressed to the all the different possibilities available for care
2	The person with dementia and the carer can, as far as possible, decide on important matters and carers must support in this both the person with dementia and the carer.
3	Feelings like anger, resistance and denial are taken into account even as differences in perceptions and perceptions of the living unit.
4	People need clear and understandable information on time and this means that the right information about: signs of dementia, the diagnosis, all the possible treatments, information for the caretaker, information on dealing with behavioral changes has to be given as soon as possible.
5	Good care means signaling and actively referring about the signals of dementia. An open discussion and referring to family doctor is also very important.
6	If needed a quick and correct diagnosis and deployment treatment is important and part of good care. That means that a diagnosis should be made within one year after first 'non-right feeling'. Many people say that they suspected something was wrong (non-right feeling) for a long time. Part of this is a proper disease diagnosis: what is the cause of the dementia? Which disease? That means that a lot of support and information, guidance and assistance is part of good care.
7	It’s important that there is always one permanent supervisor, the case manager, and a ‘living unit care plan’. That means a plan witch includes care for the person with dementia and support for the carer and the members of the living unit. That could be children! When the person with dementia dies, the carer needs after care support!

8	Good care means help and guidance about possible treatment. There has to be determined which treatment, assistance and guidance is needed in what phase and the living unit as whole should be poroperly informed about this.
9	Help should always be ‘as light as possible, as heavy as necessary’.
10	All the care is aimed at making life as enjoyable as possible. For the carer it is important that self care should always be the starting point! The carer decides what care can be given. Professional care is always supplementary!
11	All possible activities should be inventoried and fit tailore made to personal lifestyle and possibilities. That goes for social activities and more fusical activities. Meaningful daily activities to continue join the social life as much as possible and bring structure, rhythm and regularity.
12	The living unit should be fully informed about all the possibilitys for temporary full takeover of care. That goes for respite care, both incidentally or regularly, different forms of respite care at home and respite care outdoors. The combination: respite care for both people with dementia and carer together, should be offered as possibility.
13	Good care means safe and familiar living. Home ajustments for safety should be brought up when needed. The use of technique could help! If this is not possible in the own house, adapted living form or a nursing home must be considered.
14	In case of a crisis, help should be available 7 x 24 hour. This is in case of a sudden deterioration of the person with dementia or the carer suddenly has to stop caring.

(Zorgstandard dementie, Netherlands, 2013)

Appendix 5 A toolkit for caregivers of people with dementia in Hengelo

In December 2014, SIZ Twente received an order from the municipality of Hengelo to develop a toolkit for the inhabitants of this city who provide a neighbor with dementia. The assignment was carried out in close consultation with various parties in Hengelo and arose from the first results of the interviews: the need for adequate tailor-made information.

Introduction and figures

The number of people with dementia is going to increase significantly in the Netherlands in the years ahead. The latest publications on this show that the number is actually going to double between now and 2050.

'The number of Dutch people with dementia will double to half a million within four decades. The costs of caring for these people are rising to the same extent, from 7.5 billion euros a year to around 15 billion euros. ' Source: World Alzheimer Report 2010.

It is estimated that of all people between the ages of 65 and 69, over 1% suffer from dementia. The chance of dementia increases with age. For example, more than 20% of people over 80 have dementia and more than 40% of people over 90 (see Figure 1)

This development in the western world and also in the Netherlands has been calculated by TNO for the inhabitants of Twente.

Source: TNO Quality of Life 2006.

The incidence is shown below: the number of new cases per year, the prevalence: the number of occurrences in a given year and the numbers with an indication of stay, the number of required intramural beds.

A distinction has been made between the larger municipalities in Twente: Enschede, Hengelo and Almelo, and the so-called peripheral municipalities, the other 11 Twente municipalities.

The incidence in the region of Twente increases from 1217 in 2005 to 1877 in 2030. The prevalence in the same period increased from 7549 in 2005 to 11.821 in 2030.

Figures for the city of Hengelo

The prevalence figures for Hengelo show the reality:

Year	2014	2020	2030
People with dementia	1269	1378	1683
Increase in % from 2014		8,6%	32,6%

Here, also in Hengelo there is an almost doubling of the number of people with dementia. In addition to every person with dementia is a loved one who takes care of the daily care: the informal carer, usually a spouse, sometimes one of the children.

The SIZ Twente has 56 caregivers of people with dementia who are actively supported in Hengelo. The support has many forms but is always tailor-made and laid down in a support offer for the caregiver concerned.

Transitions 2015 and the consequences for this target group:

From 2015 the transitions in long-term care are a fact. For people with a less demanding and complex treatment demand, this means that they can not (yet) turn to the AWBZ and later the Wlz because the situation does not yet involve a complex demand for care. They will therefore have to turn to the municipality of Hengelo for support and guidance. The municipality of Hengelo must then provide a support offer for the person with dementia , such as day care, but also for the support of informal caregivers. With effect from 1 January 2015, this has not yet been adjusted. That's for sure. Nevertheless, informal caregivers of people suffering from dementia in Hengelo must be adequately supported in order to prevent them from becoming seriously in trouble due to overuse. This support must be lifted to a higher level.

Problem after diagnosis:

We are talking a lot with these informal caregivers, in groups or individually, from the Steunpunt Mantelzorg in Hengelo. One of the biggest problems faced by caregivers of people with dementia is the period (flat) after the diagnosis. There is a period in which the informal caregiver does not know what to do with the situation, does not know where to get help or information and therefore not where and what help is available in Hengelo.

The other side of the 'story' is that there are many support and assistance options, but the informal carer does not know where to start. Generally, people are paralyzed in the first period after the diagnosis.

Informal carers of people with dementia in Hengelo ask for a tool, a manual, a tool kit, with which they can find information about the position and the role of the informal carer and the possibilities for support available in Hengelo. This will be of great importance in 2015, because the consequences of the transitions for this target group will also be large, while the Municipality of Hengelo is not yet ready for this. Integral customization for this target group!

This tool kit is developed by SIZ Twente and is tailor-made for the Hengelo situation. It is very important to get started as quickly as possible so that the tool kit is ready for use on the day of the Informal Care worker, November 10, 2015 and can be presented!

Method:

1 An inventory is first made of the possibilities available in Hengelo for informal caregivers of people with dementia. In addition, the respite possibilities that are present or should be developed are also very important!

2 A part of the tool kit is then developed, with the emphasis on the position of informal caregivers of people with dementia. What do they all encounter, what is their own position in this and what will the development look like in the near future?

3 A design is chosen for the tool kit.

4 In each phase, the various components are discussed with a sound group of informal caregivers of people with dementia to check whether what has been developed actually gives an answer to the question.

5 The tool kit is assembled and the distribution channels are tapped.

6 The handbook is presented on 10 November 2015, the day of informal care and then widely distributed in Hengelo.

Start and duration of the project:

The project starts in December 2014 and has a lead time of 50 weeks. The completion is scheduled for November 10, 2015.

Up to date:

As part of the tool kit, at least two instructional videos can be found with subjects to be determined. We make use of modern techniques and means of communication as much as possible, while taking due account of the possibility that informal carers can not all make use of multi media! A readable (ie written) version will therefore also have to be available. A digital and easily changeable version will have to be the basis.

Young dementia:

The number of young dementia sufferers also increases in our society and therefore also in Hengelo. They are young dementia if the person with dementia has not yet reached the age of 65. About 5% of the total number of people with dementia is young people with dementia. Extra attention will be paid in this tool kit to the position and possibilities in Hengelo for young dementia sufferers.

Foundation Informele Zorg Twente

M. Garritsen, MBA, MA Managing director

Marcel Garritsen has worked his entire life in caring for people who depend on it for a long time and is currently working on a scientific study that should lead to a PhD at the University of Birmingham in the field of informal care and dementia.

On 10 November 2015, the developed toolkit was presented to informal caregivers from Hengelo during the Day of the Carers and the result was handed over to the responsible Alderman in the presence of the Mayor van Hengelo.

Appendix 6 Toolkit informal care and dementia for professionals in the municipality of Enschede

The municipality of Enschede then asked for the development of a Toolkit informal care and dementia with which professionals in the municipality of Enschede can orient themselves on the theme. Here too, a project plan was developed with a duration of the year 2016. The result will be presented at the end of 2016 by the neighborhood coaches and made available to the client.

Introduction and figures

The number of people with dementia is going to increase significantly in the Netherlands in the years ahead. The latest publications on this show that the number is actually going to double between now and 2050.

'The number of Dutch people with dementia will double to half a million within four decades. The costs of caring for these people are rising to the same extent, from 7.5 billion euros a year to around 15 billion euros. ' Source: World Alzheimer Report 2010.

It is estimated that of all people between the ages of 65 and 69, over 1% suffer from dementia. The chance of dementia increases with age. For example, more than 20% of people over 80 have dementia and more than 40% of people over 90 (see Figure 1)

This development in the western world and also in the Netherlands has been calculated by TNO for the inhabitants of Twente.

Source: TNO Quality of Life 2006.

The incidence is shown below: the number of new cases per year, the prevalence: the number of occurrences in a given year and the numbers with an indication of stay, the number of required intramural beds.

A distinction has been made between the larger municipalities in Twente: Enschede, Hengelo and Almelo, and the so-called peripheral municipalities, the other 11 Twente municipalities.

The incidence in Twente increases from 1217 in 2005 to 1877 in 2030. The prevalence in the same period increased from 7549 in 2005 to 11.821 in 2030.

Figures for the city of Enschede

The prevalence figures for Enschede show the reality:

Year	2014	2020	2030
People with dementia	1977	2054	2446
Increase in % from 2014		3,9%	24%

In the city of Enschede too, there is a sharp increase in the number of people with dementia in the coming years. In addition to every person with dementia is a loved one who takes care of the daily care: the informal carer, usually a spouse, sometimes one of the children.

In Enschede, SIZ Twente has 126 informal caregivers of people with dementia who are actively supported. The support has many forms but is always tailor-made and laid down in a support offer for the caregiver concerned.

Transitions 2015 and the consequences for this target group:

From January 2015, the transitions in long-term care are a fact. For people with a less demanding and complex treatment demand, this means that they can not (yet) turn to the AWBZ and later the Wlz because the situation does not yet involve a complex demand for care. They will therefore have to contact support teams from the municipality of Enschede for support and guidance. The municipality of Enschede must then provide a support offer for the person with dementia, such as day care, but also for supporting informal caregivers. In the summer of 2015, however, this has not yet been adjusted: the training of the professionals (read: district teams) is planned for the autumn of 2015. However, informal caregivers of people with dementia in Enschede must also be adequately supported at this time in order to prevent them from becoming seriously themselves. get into trouble because of overload. This support must be lifted to a higher level. From the autumn of 2015, the support of informal caregivers, including the informal caregivers of people with dementia, will be transferred to the district teams. Because of the burden that this group of informal carers experiences, it will be clear that this group of informal caregivers will be transferred to the district teams with even more care than any other informal carers.

Problem after diagnosis:

We are talking a lot with these informal carers, in groups or individually, from the Steunpunt Mantelzorg in Enschede. One of the biggest problems faced by caregivers of people with

dementia is the period directly after the diagnosis. There is a period in which the informal carer does not know what to do with the situation, does not know where to get help or information and therefore not where and what help is available in Enschede. The district team members, but also all care providers, will therefore have to 'identify and adequately support informal caregivers from Day 1'.
Informal caregivers, and certainly not informal caregivers of people with dementia do not report themselves soa n outreching strategy is needed.

The other side of the 'story' is that there are many support and assistance options, but the informal carer does not know where to start. Generally, people are ‘paralyzed’ in the first period after the diagnosis.
Support must start from there: the diagnosis.
For the benefit of informal caregivers of people suffering from dementia in Enschede, district members of the community and also the professional care providers will first have to identify caregivers and then support them intensively, adequately and tailor-made. This can prevent carers from becoming overloaded themselves.

To this end, a tool kit will be developed, entirely digital and up to date, which enables professionals to adequately support this target group and to reduce the load measurably.
After developing the tool kit, it will be introduced via a curriculum and transferred to the professionals: neighborhood teams and healthcare professionals.
This tool kit is developed (once) by SIZ Twente and is tailor-made for the Enschede situation.
It is very important to get started as quickly as possible.

Method:
1 An inventory is first made of the possibilities that are available in Enschede for informal caregivers of people with dementia. In addition, the respite possibilities that are present or should be developed are also very important!
2 A part of the tool kit is then developed, with the emphasis on the methodology of supporting this group of informal caregivers. This also includes the instruments developed by SIZ Twente such as measuring instruments for the load.
3 A design is chosen for the tool kit.
4 Once the various components are discussed with a sound group of neighborhood team members and healthcare professionals where clarity and usability are always central.
5 The tool kit is assembled and the distribution channels are tapped.
6 The tool kit is introduced to the target group through short training programs in the context of expertise promotion.

Start and duration of the project:
The project starts in the autumn of 2015 and has a lead time of 18 months including the transfer, the promotion of expertise to groups of district team members and healthcare professionals. The completion is planned for the end of 2016.

Up to date:
As part of the tool kit, at least there will be instructional videos with subjects to be determined. As much use as possible is made of modern techniques and means of communication.
Young dementia:
The number of young people with dementia is also increasing in our society and therefore also in Enschede. There are young dementia sufferers if the person with dementia has not yet reached the age of 65. About 5% of the total number of people with dementia is young people with dementia.
Extra attention will be paid in this tool kit to the position and possibilities in Enschede for young dementia sufferers.

Foundation Informele Zorg Twente
M. Garritsen, MBA, MA Managing director

Marcel Garritsen has worked his entire life in caring for people who depend on it for a long time and is currently working on a scientific study that should lead to a PhD at the University of Birmingham in the field of informal care and dementia.

Appendix 7 Letter Concerns Plan of Program Langer Thuis

The President of the House of Representatives of the Staten General
PO Box 20018 2500 EA THE HAGUE
Visiting address Parnassusplein 5 2511 VX The Hague
www.rijksoverheid.nl

Date 5 November 2018
Concerns Plan of Approach Program Langer Thuis

Dear Chairman,

With this letter I inform you about the state of affairs of (and the plan of approach to) the Langer Thuis program.

On 18 June, the Langer Thuis program was launched as one of the components of the Pact for Care for the Elderly. In the program, I have indicated that I will work out the program together with the parties involved Over the past few months, 21 parties have worked hard on this. Always from a single connecting goal: that older people can grow old in their own familiar environment, with a good quality of life.

For a very important part, the Langer Thuis program is on local and regional level: care providers, care providers, social neighbourhood teams, welfare workers, volunteers, municipalities, housing corporations and insurers are involved. They are and feel responsible for ensuring that support and care are available at the level of the neighbourhood and region - where the elderly live - and that housing and the living environment are suitable. That is why the Action Plan seeks to support and accelerate together with local and regional parties - who are fully engaged in tackling this task together with the elderly themselves.

At the administrative meeting of 1 November last, the parties involved committed themselves to the plan of action. For each action line, goals are formulated and each goal consists of multiple actions. The parties are bound to each action, ownership is vested and milestones have been appointed. If in the course of time it appears that additional actions are possible and / or necessary, they can be agreed upon further. In that sense, the plan is "a living

document". This plan of approach serves as a guide for the implementation of the Langer Thuis program in the coming years.
Parallel to the elaboration of the Plan of Approach, I have been hard at work in the past few months to initiate the intentions of the Langer Thuis Program. I take this opportunity to inform you about the status of a number of actions from the Program.

Action line 1 Good support and care at home

- Creating **awareness** among the elderly We expect to be commissioning KBO-PCOB this year for the design and development of the 'Vitaler old' network. The network will mainly focus on prevention, with the aim that the elderly remain independent, independent and healthy for as long as possible. The goal is to start local and national partners with local practical initiatives and experiences aimed at prevention in seniors, to bundle, to share and to boost, so that they really reach the elderly.
- Regional cooperation between municipalities and insurers Health insurers and municipalities have agreed that they will strengthen cooperation in the region and work as quickly as possible towards national coverage in the cooperation. For three themes that are important to them: **mental health care, geriatric care and prevention**, they will make a work agenda by the end of February, including planning. The focus here is learning from where things are going well and scaling up and broadening, specifically on the points:
Strengthening cooperation: what makes it work well together?
Scaling up: how can good agreements and initiatives be scaled up and spread to other municipalities and health insurers? In doing so, they make an updated overview of the regional partnerships and examine how they can be strengthened.
- Promoting the use of **e-health by the E-health Home incentive scheme** The e-health at home (SET) incentive scheme, for which € 30 million will be available each year over the next 3 years, gives an impulse to the widespread and structural deployment of e-health health in the regular care and support of people with a chronic illness or disability who live at home. E-health can increase the effectiveness of care, maintain or improve quality and ease the overstrained labour market in the care field. **For the elderly and their informal carer, eHealth contributes, among other things, to more direction and more freedom of movement, and ensures that elderly people with a higher quality of life can live at home longer.** Thanks to e-health, professionals have more time for good care for the elderly, they experience less work pressure and more satisfaction in their work. From the scheme, a total of around 280 initiatives can be funded that focus on a better quality of life for people through scaling up and securing e-health in practice. The draft regulation text of SET will be presented to interested parties in the field for consultation in the coming weeks. Your

House will be informed in early 2019 about the exact details of the regulation. The scheme is therefore open to applicants.

- Facilitate the exchange of information between client and professionals and between professionals through the InZicht innovation scheme. It is also my intention to open the InZicht subsidy scheme at the start of 2019. An additional € 30 million will be available annually for the next 3 years. I have carried out a baseline measurement on this and informed you on 16 October.3 The purpose of the InZicht program is to contribute to a better quality of life for the client in long-term care. By accessing and exchanging (health) data, the decision of the client (or his representative) together with the professional is supported. In addition, digital data exchange (particularly through the exchange between professionals) contributes to improving the perceived quality of care, the well-being of the client and a reduction of the workload for the professional. By December 2018, small pilot projects will start in which the data exchange will be demonstrated in practice. Experience is gained in these pilot projects and insight is gained into what is needed by healthcare providers to speed up data exchange. There is room for 20 experimental garden participants. In practice, for example, work is being done on an arrangement that fits well with what is needed. A first part of the scheme will be opened early next year for the entire long-term care sector and then about 1200 providers (in partnership) have the possibility to apply for a subsidy. You will be informed about this in the spring of 2019.
- More space in the contracting for the use of specialists in geriatric medicine in the first line and acute chain (now by care offices) An extra € 6 million has been structurally made available on an annual basis for the use of specialists in geriatric medicine in the first line and the acute chain. This was achieved at the end of October via an increase in the subsidy scheme for extramural treatment4. Care offices now have clarity about the size of the (increased) budgets and can start contracting for this care by 2019.
- More up-to-date insight into the right available care places in the region by widening the regional **coordination function for temporary stay**. Health insurers and healthcare providers have implemented regional coordination functions as of 1 April 2018, so that available capacity in the first-line accommodation for each GP and every hospital in the region is clear. Now it is important to ensure that the coordination points work more widely, because there are more forms of temporary residence. Last summer, the parties agreed that the widening must in any case include all non-conceivable forms of care with a temporary stay with at least the following tasks: providing current insight into the coordinated forms of care with a temporary stay; having 24/7 availability and having 24/7 recording; support with the assessment of the right care; and monitor and evaluate.

This means that the referring party only needs to call one number and does not have to spend a lot of time arranging the necessary care. It would be nice if the connection was sought with district nursing / home care. ZN takes care of boosting the widening. Adequate financing of the coordination function is therefore important. A structural solution is being worked on. There are several temporary and not ideal options for financing available, in addition to financing via the rates.

- Strengthen regional consultation of acute care chain (ROAZs) in the acute care chain through legislation. In 11 regional consultation acute care chain (ROAZs) agreements are made about the availability and accessibility of acute care. The field of work of the ROAZs has recently become more extensive. Due to the hustle and bustle of acute care, there is more and more collaboration with parties outside acute care, to prevent unnecessary intake of acute care and to promote outflow from acute care. The pressure in combination with the shortage on the labour market makes cooperation in and around the acute care chain more important and complex. In order to do justice to the increased tasks of the ROAZ, regulations will better define what those tasks are, who should be involved in the ROAZ and what needs to be done if the continuity of acute care is at stake. GPs and GPs will also have to become involved in the ROAZs and be involved. We are working on a draft AMvB. In addition, the AMvB is related to the legislative proposals on the accession of healthcare providers / Act on adapting health care providers. My colleague Bruins will send the AMvB draft to the Chamber in November.

Action line 2 Informal care and volunteers in care and welfare

- Organizing meetings where informal caregivers can meet and **empower each other** On 1 October, the documentary 'Moeder aan de lijn' was premiered at the Dutch Film Festival and was shown on TV a week later by broadcaster HUMAN. The documentary is part of a number of national and regional informal care meetings, which are financially supported by me and involve a variety of parties relevant to informal caregivers, including WeHelpen and local support centers. The documentary was viewed more than 250,000 times at the NPO. In October and November, meetings will take place through the country, in order to conduct interviews with informal caregivers on the basis of fragments from this documentary and a portrait made per city about what informal care means, what they need and what support is possible. .5 The attendance of the meetings in Groningen, Maastricht and Den Bosch was high with about 100 people per meeting and was also well appreciated. An essential element in the meeting is that informal carers meet and share experiences. At the same time, it proves to be useful that (local) organizations are involved that can further help the informal carer.

At the same time, **positive aspects of caring and the perspective of action are highlighted**. There will be meetings in Barendrecht, Arnhem and Amsterdam.

- **Bring informal care to the attention of employers and working caregivers** With the multimedia campaign 'How the Netherlands works', SZW and VWS have been promoting the dialogue since 2017 about combining work and care tasks. This can concern care for children and informal care. On the basis of videos, tweets and experience stories on the website hoewerktnederland.nl and on Facebook and Twitter, the dialogue is conducted online, which contributes to making the combination of work and care on the work floor open to discussion. An employer who has an eye for his informal carers, who makes it open to discussion and offers scope, gets a committed employee who will keep up for longer and does not get stuck in a burn out. The posts on Facebook and Twitter reached 957.074 and 26.591 people respectively in the third quarter of this year. The reach via Facebook is 73,621 people per week and 2045 people via Twitter.

The activities of Stichting Werk en Mantelzorg, which I also support, are actively aimed at employers and offer tools to give shape to a caregiving-friendly employer.

- Boosting the supply of **respite care** through a national booster respite care I want to appoint a respite respite care this year. The respite of respite care will go into the country to support municipalities in collaboration with the (regional) municipalities and with (experience) experts, to further develop a low-threshold, good and varied range (local and regional), with room for customization . This can vary from **temporary staying outdoors to extra support in the home situation and all variants in between, if only it gives a breathing space to the informal caregiver.** The range that will be realized in this way will be better suited to the wishes of both the informal carer and his / her neighbor (s). In doing so, attention will also have to be paid to the perceived threshold to hand over the care (completely). I will keep your Chamber informed about the progress that the respite manager is making.
- **Improve support caregiver through experiments social approach dementia** The first phases of the experiments were started in Amsterdam, Amstelveen, Rotterdam and Den Bosch. In the experiments, attention is paid to supporting the (informal) network, meaningful daytime activities and help in daily life. The experiments are based on the theory of Professor Anne-Mei Thé. People with dementia, due to their increasing cognitive limitations - more than others - benefit from care that fits in with their own environment and that of their loved ones. In addition to regular medical care, people with dementia also need more social support in ordinary, daily life. For example, more attention needs to be paid to the disruption that dementia entails and the changing relationships with family members.

- **Support Local volunteer policy** It is important that municipalities create the best possible conditions for the local deployment of volunteers in many sectors such as care, education and sport. Movisie is currently carrying out an inventory of the way in which municipalities implement their volunteer work policy. Elements of this policy can be for instance (financial) support of voluntary organizations, setting up a volunteer (support) point and / or taking out voluntary insurance. Based on the outcomes of the research, we want to look with municipalities, voluntary organizations and the umbrella organization NOV which actions can be initiated to generate more attention for (the importance of) adequate volunteer work policy. The latter will be further developed in 2019.

Action line 3 Living

- Forming new residential (care) forms by setting up incentive scheme. Both in the planning phase and in the construction phase, residents' initiatives and social entrepreneurs have problems to get financing around. The incentive scheme aims to help these initiatives in financing with a guarantee or loan. Usually an initiative consists of 25 to 40 homes. It is expected that around 50 initiatives can be helped annually in the planning or construction phase. The scheme is now being developed and coordinated with the parties involved. It is envisaged that at the start of 2019 an appeal can be made to the scheme. In addition, we examine how innovation can be achieved with regard to exploitation models, making the demand transparent in the neighborhood and the approach to the neighborhood. This involves organizing challenges.
- Establishing the support team Both when mapping the local task and when applying an approach to enable people to live in a suitable way, an important task lies with municipalities. Municipalities that need this, we offer help to make a start. We are making an inventory of the need for municipalities. This may also involve supporting civil servants with the work of making a local living-care vision, if necessary in combination with the knowledge program. We expect that this team will be operational at the beginning of 2019.
- Community of Practice (Who Cares) On September 1, 2018 the Chief Government Architect started the Community of Practice. The community is a network that must ensure that the new forms of living and care that are conceived are actually created. The community supports designers and care experts in carrying out new forms of housing and care and future-proof neighborhoods and stimulates new initiatives. In addition, the Government Architect, together with the Ministries of the Interior and Kingdom Relations and the Ministry of Health, Welfare and Sport, talks about the realization of the prize-winning projects in the municipalities of Rotterdam, Almere, Groningen and Sittard / Geleen.

- Annually 10 good examples Platform 31 sets up a program of experiments that should lead to 10 good examples of new forms of housing and care for the elderly every year. The aim is to make clear what an initiative is against when designing a concept and how to deal with it. In addition, a knowledge program will be set up in which good examples will be developed with regard to mapping out the local task and a local approach to help older people live suitable. Here contact with the G40 is about a joint knowledge program. By the end of 2018, the assignment will be ready for the knowledge program.

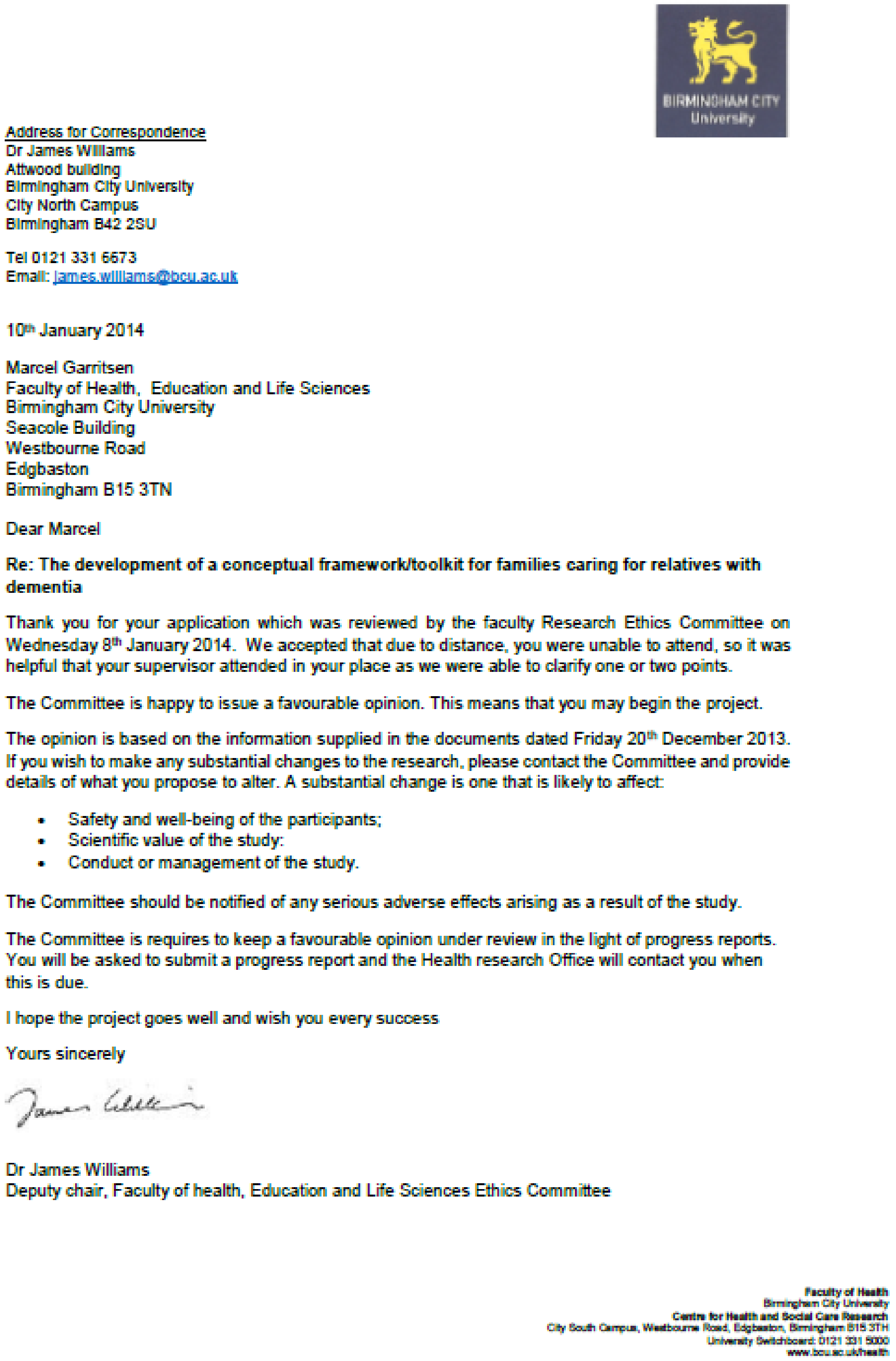
Finally, I thank all parties involved for their efforts and contribution to the plan of action. For the summer of 2019 you will receive a program-wide progress report, in which the first baseline measurement will also be included.

Yours sincerely,

the Minister of Health, Welfare and Sport,

Hugo de Jong

Appendix 8: Ethical permission



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10th January 2014

Marcel Garritsen
Faculty of Health, Education and Life Sciences
Birmingham City University
Seacole Building
Westbourne Road
Edgbaston
Birmingham B15 3TN

Dear Marcel

Re: The development of a conceptual framework/toolkit for families caring for relatives with dementia

Thank you for your application which was reviewed by the faculty Research Ethics Committee on Wednesday 8th January 2014. We accepted that due to distance, you were unable to attend, so it was helpful that your supervisor attended in your place as we were able to clarify one or two points.

The Committee is happy to issue a favourable opinion. This means that you may begin the project.

The opinion is based on the information supplied in the documents dated Friday 20th December 2013. 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:

- Safety and well-being of the participants;
- Scientific value of the study:
- Conduct or management of the study.

The Committee should be notified of any serious adverse effects arising as a result of the study.

The Committee is requires 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.

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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