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**CLIENT-CAREGIVER RELATIONSHIPS IN DEMENTIA CARE: THE
EXPERIENCES AND PERCEPTIONS OF HEALTH CARE
PROFESSIONALS.**

By Megan Nicola Downes.

*A thesis submitted to the University of Huddersfield in
partial fulfilment of the requirements for the MSc by
Research in Psychology.*

January 2020

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Client –caregiver relationships in dementia care: the experiences and perceptions of Health Care Professionals.

At present, the practical use of person-centred care principles in health care facilities is provoking the need to explore the relational aspects associated with leading dementia care practice. Alzheimer's Society UK states how dementia is becoming one of the leading causes of death along with the prevalence of the disease set to rise. The current research aims to explore the lived experience and how participants make sense of client-caregiver relationships in dementia care. An interpretative phenomenological analysis was chosen for this study as it focused on understanding the meanings attributed by participants towards relationships in dementia care. Five participants were interviewed using semi-structured questions designed by the researcher. Each interview lasted approximately thirty to fifty minutes and were analysed using IPA. The close analysis of the five interviews produced four superordinate themes:

1. Trying to remain positive: 'glass half full in all situations.'
2. Experiencing variety: workdays, individuals and reactions.
3. Emotional intelligence: caregivers experience suppressing their own emotions and maintaining the human relationship.
4. Growth aspirations: developing self as a caregiver through the experience of time.

The results suggested that the participants believed relationships to be a valuable aspect concerned with the delivery of person-centred dementia care, while highlighting factors which affect both the well-being of the residents and the staff. Recommendations for practice suggest questions regarding the effectiveness of psychological training. Such as, balancing clinical detachment and empathy to optimise the provision of care for residents. Also addressing the need for stress management/awareness in mandatory training for health care assistants. Finally, this research acknowledges the need for future research in key areas of dementia care practice such as time, staff-wellbeing, and training.

Keywords: dementia; Health Care Professionals; Interviews; qualitative; IPA; perceptions; experience

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Chapter 1: Introduction

Dementia is one of the biggest health problems of our time. Experts suggest the number of people living with dementia in the UK alone is expected to rise to 1 million by 2021, with almost one in eight people dying from the disease in 2018 (Hill, 2019). Chapter one will introduce some of the key areas concerned with the topic of relationships in dementia care. It will cover key background literature, policy and developments in dementia care, also offering an insight into the researcher's position and motivations to study the field. The chapter will then conclude with a thesis overview and summary.

Background

I currently work as a Senior Health Care Assistant based within a residential dementia unit. Prior to this, I worked as a domiciliary Health Care Assistant (HCA). Many of my home visits involved caring for individuals living with dementia in their own homes. As one can imagine, for a newly trained HCA with no medical background, walking into an individual's home for the first time can be quite daunting, even more so when you discover the service user is living with dementia.

Despite having an awareness of the disease and a common-sense approach to caring for the individual, I faced many challenges including, aggressive behaviour and noncompliant service users. I soon discovered that the more I visited the same service users, the easier it became to provide the care that was required. When I began to build a relationship and a sense of trust with the individual, carrying out personal care and other care requirements became a lot less challenging. Building a good relationship with the service user appeared to be an important factor for both myself and the individual. It was often the case that the families also felt this way too. I enjoyed helping these individuals. I realised what a difference caring for those living with dementia made on a daily basis.

I also experienced these feelings working in residential care. The more I got to know the residents the more gratifying the job became and despite the challenges Health Care Professionals (HCP) encountered, I came to understand the importance of building a good relationship with the resident. Despite this, I often felt it was easy to fall into the routine of the working day, ensuring all the tasks for that particular shift are completed before hand over. I often found myself empathising with the residents and how they might have felt during a shift, when there are particular time constraints for particular tasks, such as personal care, meal times, etc. In my experience, I have noticed conflicts between working towards the routine of the working day and working in a person-centred way. I have often found myself compromised between these decisions. As a result, I find myself sympathising with the need to build on previous research to explore ways to improve person-centred practice.

Through experience and observation of the residents I have worked with, I have learnt that living with dementia has a large impact on relationships. Therefore, an understanding of both what it is like to live with dementia and to care for someone with dementia is a crucial element to be explored before conducting the research. The most common symptom linked with dementia is memory loss, meaning the individual may start to forget the names of the people they once knew. Short-term memory is frequently affected with dementia, those living with the condition may show signs of repetitive conversation or misplacing objects or an inability to keep track of time (Shea, 2012:2011). Dementia can also affect what someone says or does and the experience of dementia is different for each individual. The individual's relationships differ with the people around them, whether it is loved ones, friends, family, or, caregivers and this can soon change for a variety of reasons. Eventually, the person with dementia will come to depend more on the other people in their life. This can lead to difficulties which can then put pressure on relationships. Dementia affects one's ability to communicate, which creates frustration as communication is so important in any relationship.

As a result, the current study would like to pay close attention to how relationships are perceived and experienced by other health care professionals alike. With my experience in

mind, I aimed to explore other HCPs understanding and experiences in a similar field, in order to establish some meaning in the way in which HCPs viewed relationships in dementia care, whilst gaining an empathic understanding for the experience itself.

Current developments towards strengthening caregiving relationships

As the current research is exploring the lived experience of relationships in dementia care, I thought it would be appropriate to focus on exploring current developments which have been conducted to aid with the development of relationships in dementia care. As the world's populations continues to age, the prevalence of dementia is on the rise. Research is beginning to realise the need for sustaining communication and connection. This trend is congruent with the prevailing needs for compassionate caregivers and the decline in the number of caregivers, in order to meet the cumulative prevalence of individuals living with dementia (Mordoch et al., 2012).

At the moment, health care is slowly moving away from bio-medical models and patient focused approaches are becoming more prominent in clinical practice (Brocki & Weaden 2006). Fischler (2017), highlighted how there is growing evidence for non-pharmacologic therapy for dementia patients with limited research focusing on supporting their care-givers mental stress. In 2016, Health Quality Ontario introduced the first provincial quality standards for the treatment and assessment for the behavioural symptoms in dementia. They composed fourteen statements which provided definitions and indicators which allowed health care organizations to measure adherence (Fischler, 2017).

In an age where technology is rapidly developing, Mordoch et al. (2012) explored the use of social commitment robots in the care of elderly people living with dementia. In respects to the wider issue of the development of relationships, the use of social commitment robots may be beneficial in connecting caregivers and patients through a shared interest in new technology, while reducing the pressure on caregivers to attend to the emotional demands of those living

with dementia. The article highlights how research into areas such as gerontology and robotics need to collaborate in non-traditional ways, such as robot therapy, in order to manage some of the problems related to dementia.

Mordoch et al. (2012) discussed the ethical considerations which are vital to reflect upon. They reflect on how the use of social commitment robots to meet the companionship needs of elderly people living with dementia needs extensive monitoring and careful considerations. They also agree that innovative new ways of managing health care situations for this population are needed, highlighting how social commitment robots are a means of providing alternatives to some of the care demands.

Roger et al. (2012), also described the use of technology. However, they pay attention to the role of personhood in dementia care, which is an ideal this project appreciates. This particular article discusses the use of a small table-top robot named 'Paro'. Takanori Shibata, the developer of this model, refers to Paro as a "social commitment robot" (Roger et al., 2012. p. 18), which is used to reflect the concept of a person having a social relationship with the robot. They explain how the robot looks, feels, and acts lifelike, with motorised moving parts which allows it to move autonomously. The robot also appears to learn behaviour and display emotions and takes the shape of a baby harp seal.

One can see the benefits of using social commitment robots as a means of promoting communication and interaction between staff, families etc. It is also a useful tool to consider in the development of meaningful relationships in dementia care. However, the article recommends ongoing research to examine the benefits and potential risks of using 'Paro', especially for individuals living with dementia. At the same time, it argues that the interest in how robotics can enhance care in homes is growing, and that Paro and similar robots may be changing the daily lived experience of individuals living with dementia (Roger et al. 2012). However, this is an American development, therefore the use of such technology in British health care practices, needs further exploration to assess whether the use of social

commitment robots would aid the development of relationships. Once more, an exploration into British cultural views regarding the use of technology in health care practice, would also be beneficial in understanding current perspectives on technological advancements such as these.

Care standards approach and government policy

Health care standards and government policy are vital part of the health care system, they help health systems develop and evaluate essential topics such as leadership, infection control/prevention, and medication management. These are important as they ultimately affect the quality of services that the public receives. They are the foundations which can create a strong health care structure that everyone concerned can rely on and inform the public of what level of quality to expect from a service provider. Given the underlying motives behind the current study, gaining an insight into what policy and standards affect those living with dementia is essential to reflect on as care standards and policies are the foundations of which HCPs adhere to.

Over the past decade, the government have introduced government policies and campaigns with the sole aim to improve dementia care, support, and research in England. The table below outlines these;

Table 1 –Dementia specific policies and campaigns.

| <u>Policy/Campaign</u> | <u>Aims</u> |
|---|--|
| The National Dementia Strategy 2009 | <ul style="list-style-type: none"> • Raise awareness of dementia and remove the stigma surrounding the condition. • Improve diagnosis rates for people with dementia. • Increase the range of services for people living with dementia and their caregivers. |
| The 2012 Dementia Challenge | <ul style="list-style-type: none"> • Creating dementia friendly communities that understand how to help. • Driving improvements in health and care. • Better research and increased funding into care, cause, and cure. |
| The Challenge on Dementia 2020 | <p>Two key objectives set out by David Cameron: stated that by 2020 he wanted to be;</p> <ul style="list-style-type: none"> • The best country in the world for dementia care. • The best place in the world to undertake research into dementia and other neurodegenerative diseases. |
| Dementia Friends and Dementia Friendly Communities 2014 | <p>Alzheimer's society launched a campaign to recruit one million Dementia Friends who are able to recognise symptoms and support those living with dementia. As of January 2019, there are 2.78 million Dementia Friends.</p> |
| Dementia Research 2019 | <p>In May 2019, parliamentary question response provided information regarding government funding for dementia. NIHR funding for dementia research was £43.0 million in 2017/18, having increased from £27 million in 2013/14.</p> |

The National Dementia Strategy provided 17 recommendations which the government want the strategy to achieve. Some examples of these recommendations which relate more specifically to this project's research include; easy access to care, support, and advice after diagnosis, improve the quality of life for people living with dementia in care homes, and an informed and effective workforce for people with dementia. This particular strategy aims to improve the lives of those living with dementia over the next five years. However, Evan (2014) expresses her concerns in that less than one half of individuals in the UK with dementia receive an official diagnosis of dementia. As a result, she explains how the lack of diagnosis means that help and information that could be made available were not forthcoming.

Evan (2014), also highlights how availability of resources has decreased since the National Dementia Strategy was introduced and emphasises the importance of what happens after a diagnosis. At the time, this was a big leap in the awareness and attention given to dementia care that can be noted as a worthwhile step towards increasing the profile of the disease. The 2012 Dementia Challenge details some of the governments' achievements since the 2009 strategy. For example, reducing the use of anti-psychotic medications for people with dementia. However, when we arrive at the Challenge On Dementia 2020, the government have only published phase one of its review of the Challenge on Dementia 2020 in 2019 and we are yet to anticipate the review of 2020, of which since the objectives were put in place, we have had two Prime Ministers, meaning the extent to which the 2020 challenge has achieved its objectives still remains uninformed.

As this particular research is exploring residential dementia care, it is important to consider the specific policies related to dementia care in residential settings. All care homes have to be registered with the Care Quality Commission as this demonstrates that the home has met the legal obligations which is regulated by the Health and Social Care Act 2008, Care Quality Commission (registration) Regulations 2009, and the Health and Social Care Act 2008 (regulated Activities) Regulations 2014.

For Example, The Quality Care Commission 'Shaping the Future' report for 2016 to 2021 proposes a five year strategy with various ambitions for the future of Health Care Services. Their ambition includes; "a more targeted responsive and collaborative approach to regulations, so more people receive high-quality care." (CQC, 2016:2021. p. 3). The aim to achieve this particular ambition is driven by four main priorities, for instance, "promote a single shared view of quality' and 'encourage improvement, innovation, and, sustainability in care" (CQC, 2016:2021. p. 11). They believe they will achieve these goals when; organizations deliver care, improve quality as a result of CQC's regulations, when people trust, and use their expertise in practice. Furthermore, CQC released a State of Care Report for 2017/18, which explores the standard of care providers across England. The report states how most people in England receive a good quality of care. However, its authors are aware that the quality of care is not consistent. In this particular report, they explore the challenges faced for local health and social care organisations. They highlight the need to focus on finding sustainable solutions which put 'people' at the centre point. The State of Care Report 2017/18 pinpointed five factors which, ultimately, affect the sustainability of good quality care for individuals. Some examples include; access to care, support, workforce who deliver care, funding, and commissioning.

According to a more recent report from the Dementia Action Alliance, the National Service Framework for Older People (2001) was reviewed in 2010 and stated that there was in fact a positive progression in services, yet a lack of implementation in certain aspects of dementia care still remains. This particular framework aimed to promote good mental health in older people.

A National Dementia Declaration was introduced in October 2010 which outlined seven outcomes individuals with dementia and their care-givers state they wish to see in their lives. This includes values such as; having personal choice, having support to help them live their lives and living in an enabling and supportive environment.

However, The Francis report, 2013 states how up to 1,200 individuals died unnecessarily in appalling circumstances in the Mid Staffordshire NHS foundation Trust Hospitals between the years of 2005 and 2009 (Roberts, 2015). The report itself gives 290 recommendations which were designed to change and make sure the patients came first. Despite the efforts being made to improve the lives of those using Health Care Services, there are still cases of unnecessary incidents taking place across Health Care Services. The report states, how these incidents occurred between the years of 2005 and 2009, which is around the time the National Dementia Strategy was introduced in 2009, however, in the past three years there are still reports in the media of bad quality care across the UK. For example, in January 2020 the chronicle released an online article concerning a senior nurse jailed for subjecting residents to horrific abuse in care homes. Examples such as these, indicate that it should be a fundamental priority of the government to address these issues promptly, and evaluate the current policies in place in health care services today in order to prevent horrific case like above from happening.

Thesis Overview

On a final note, an exploration into the current and past policies in place for dementia care provides a useful background to what is currently in place for those living with dementia. With regards to the motivations for this project, this chapter has investigated some of the current developments, policy, and current actions in practice, therefore, opening doors to explore some of the current issues surrounding dementia care practice which may contribute to the overall development of client-caregiver relationships. Chapter two will discuss the current and past literature relevant to our understanding of the client-caregiver relationship, paying particular attention to dementia care environments.

In regards to conducting the research, chapter three elaborates on the use of qualitative method, and how it allowed the researcher to access a more in-depth analysis of the perceptions towards the phenomena. This is later covered in the results section of chapter

four. Prior to conducting this project, I had a little background knowledge in Interpretative Phenomenological Analysis from conducting an undergraduate project. I was aware that IPA was suitable for analysing experience, therefore, I appreciated how the idea behind this current research would focus on the experiences I had previously had in health care, making this choice of method the most appropriate. Chapter three also discusses the finer details regarding the methodology of the research and how the research was conducted. It also explores how I addressed any ethical concerns relating to proceeding with the research project.

Chapter four presents the findings from the interview study, relating to the experiences of a typical working day in residential dementia care. It also offers some perceptions on how they conduct themselves personally, highlighting particular emotions and feelings towards relationships with residents and other aspects of their job role. It also discusses the interviews in greater detail, offering extracts from the interviews, followed by a phenomenological interpretation on behalf of the researcher. The interviews also provide an insight into the future of care-giving relationships in dementia and the participants' perceptions and thoughts regarding what this could look like.

Chapter five discusses my findings from the interpretative analysis of the participants' accounts in relation to practice. This is combined with some critical discussion of previous literature in the field. It discusses three key concepts which were found to be the main contributing factors to achieving an effective dementia care environment in practice; *time*, *training* and *staff well-being*.

This chapter will focus on reviewing previous literature in the area of relationships in dementia care. This involves the assessment of how relationships play a vital role in dementia care practice. This literature review aims to search for articles relating to HCPs experience of relationships. To assess the literature I began by using the university search engine, Summon, using key words related to the field. I then broadened my sources to google scholar also using books from the University of Huddersfield's library. A great deal of the literature I found was qualitative, this corresponded well, given the chosen method for this research. I would like to focus this literature review on current studies from the perspectives of:

1. Living with dementia vs caring for someone with dementia.
2. Understanding the development and contribution of relationships in health care.
3. Relationships and dementia.
4. Morality and ethics in caring.

Research literature is increasing in its acknowledgment towards valuing the relationships between the people living with dementia and their care-givers. They are also beginning to connect the experience of both perspectives. Furthermore, there is a plethora of theoretical literature which explores theory and the practice of 'person-centred care' (PCC). This is one of the underpinning rudiments associated with the development of relationships in care. This is central to the current research and will be explored in the latter part of this chapter (Goodrich & Cornwall, 2008). PCC has been defined and perceived in literature from a variety of angles. As an illustration, patient-centred, person-focused care, and patient-directed care. These definitions stimulate much debate/review about the most effective and meaningful definition for the concept. Brummel-Smith et al. (2016), described PCC as allowing individuals values and preferences to be expressed. Therefore guiding all aspects of a person's care, whilst supporting their realistic health and life goals. They explain how PCC is achieved via dynamic

relationships among individuals, loved ones and relevant providers. Suggesting how this collaboration informs decision making to the degree that the individual desires.

Furthermore, despite finding a useful amount of literature regarding experiences of person-centeredness in practice and the experiences of health care, all of which correspond well with the aims of this research. My overall interpretation of the literature review is that, despite finding many studies concerning the exploration of relationships in dementia and health care practice. These studies have not fully evaluated their use, or, been implemented in day to day practices and training. For example, coming from a health care background myself, the research I have found, has only come to my knowledge via carrying out this research project and researching the topic independently. This perhaps highlights how there is still currently a gap between theory and practice, which perhaps links to some of the issues health care providers face today in practice.

Living with dementia Vs caring for someone with dementia

Wijngaarden et al. (2019), explored the experience of living with dementia using an existential phenomenological approach based on narrative accounts of people living with dementia. Their results concluded that living with dementia can be understood as an ongoing, severely disruptive experience and the individuals concerned find themselves in a very uncertain, unpredictable, and ambiguous period of life. They described how the individuals can experience a variety of losses that change their relationships with others and the surrounding world they live in. They also explain how the relationship with themselves and their body changes significantly.

Wijngaarden et al. (2019), offers some insight which relates to the current study as the current study aims to focus on lived experiences. Therefore, by being able to look into how dementia is being experienced first-hand by the individual living with dementia, HCPs can gain a hypothetical understanding of what it might feel like to live with dementia, which may deepen caregivers understanding of the patients' needs.

Similarly, Aldridge et al. (2017) explored experiences of dementia-related shame for those living with dementia. The study captured four superordinate themes which captured the key experiences of the phenomenon. For instance, “avoidance, loss of control, trust, and relationship matters” (Aldridge, 2017. p. 1). These involved experiences of negative self-perceptions, such as feelings of meaninglessness, uncertainty and issues with relationships; like feeling a burden to loved ones. Their findings embrace some value on the promotion of non-shaming experiences for people with dementia, which can be facilitated through encouraging better communication from HCPs and increase awareness of shame in dementia. The study highlights how participants place an importance on relational issues. This supports the current study’s objective to focus on deepening the understanding of how relationships are being experienced in dementia care. Despite, the study revealing insight into a sensitive area of research which is less explored, it is difficult to assess and define the experience of dementia-related shame. This is because the participants themselves are living with memory problems. The extent to which the participants demonstrate an awareness of their dementia may be difficult to evaluate, given the nature of dementia itself.

Additionally, Clare (2002) reflected on the coping resources of those with early onset of Alzheimer’s disease. This study aimed to understand how people with early-stage dementia attempt to adjust and cope to the diagnosis. She believed this was a vital starting point in developing interventions that can increase self-efficacy and adaptive coping, also, explaining how her results demonstrated how participants’ attempted to adjust to the onset of memory problems. These findings were categorised into themes, such as, holding on, compensating, fighting and coming to terms. This particular article provided a foundation for developing interventions that can increase well-being for those living with dementia. However, it is limited to the perspective of coping with early-stage dementia. This means we cannot apply this research to coping with late-stage and end of life stages of dementia. Attempts to gain an awareness into how people cope with early-stage dementia can be beneficial to HCPs and the current study of relationships in dementia care. For example, when an individual reaches

late-stage and end of life dementia, the practicalities of exploring that persons coping resources becomes more difficult. This is due to the fact that a person's natural ability to communicate with those around them decreases as the dementia progresses. As a result, an awareness of the feelings towards coping in early-stage dementia can act as a useful foundation for building relationships between HCPs and those living with dementia.

Knowledge regarding how a particular person with dementia feels about coping, allows for the caregiver to empathise with that person, thus creating a stronger relationship. Additionally, it provides a starting point which can be elaborated on when exploring coping strategies in later-stage and end of life dementia. However, further research is required to assess how people cope with later-stage/end of life dementia as it is more difficult to assess. Therefore, developing interventions to increase well-being will be more difficult to evaluate in cases of late and end of life dementia.

On the contrary, Quinn et al. (2009) explores how caregiving is perceived. They suggested that caregiving can have positive outcomes, such as, feelings of gain or gratification. They highlighted how qualitative studies can also agree for a more in-depth examination of how dementia affects relationships. Similarly, William et al. (2009) pointed out how in order to transform and develop the patient's experience of health care, and to provide care with compassion and dignity, then we must pay attention to 'relational practice' more fully. Also, explaining how its nature should be more clearly articulated, in order to be recognised as a core competency within all health and social care disciplines.

However, Decker (1997), highlighted how residential nursing is considered to be particularly stressful and that health care providers/assistants find themselves conflicted with remaining person-centred in practice. Zimmerman (2005), would support this claim as he believes work stress is reported higher in facilities within specialised dementia units. He highlighted how those that work on specialised units face a variety of stressors. Some of these stressors include; understaffing, inexperienced co-workers, dissatisfactions related to work flow, residents who are unappreciative or uncooperative, families who may complain a lot or need

emotional support, and unmet expectations. Zimmerman (2005) also reported, how studies with residential-aged care and nursing staff demonstrated higher levels of stress in younger care assistants, indicating how age and work experience are two demographic risk factors contributing to work stress. One can link Zimmerman's (2005) research to the current study as the participants recruited for my own research, vary in both age and levels of experience, some of the key elements explained above which relate to work stress are explored in the participants accounts of the experience, this is discussed in chapter four.

Similarly, Quinn et al. (2009), explored the quality of relationships, by exploring the experiences and well-being of care-givers of people with dementia. They discussed how their findings signposted that relationship quality should be encompassed in models of stress and coping in caregiving. Furthermore, Fukuda et al. (2015) explored the issues experienced when administering care to those with dementia in acute care settings. They discussed previous studies depicting how ethically difficult situations can often lead to cases of abuse and cases of disorderly conduct among patients with dementia. With this in mind, further discussions are made regarding the issues health care staff face when caring for those living with dementia. Some examples of issues discussed include; frustrations with time, responsibility for patients, frustrations with lack of organization, divided tasks, and working alone.

Fukuda et al. (2015) discussed the complications that derive from the continually changing needs of patients with dementia, which may affect the organisational structures of the faculties. They also explored factors which influence the management of patients living with dementia, such as, time pressure, work load, limited resources and finally a lack of knowledge of dementia among medical, nursing, and other HCPs (Fukuda et al., 2015, cited in Fossey, 2006). The management of patients living with dementia, is relevant to the current study as many of the influencing factors explained above, are explored in the participant's interviews. However, further research is required to perhaps assess the frequency of risk assessments in dementia care, as the needs for a person with dementia are continually changing as the

dementia progresses. An exploration into just how often risk assessments are taking place in dementia care facilities may link to the stress factors associated with managing the condition.

Understanding the development and contribution of relationships in health care.

This subdivision of the literature review motivated particular areas of interest concerning the motivations for this research project. As it is key to explore the relational aspects associated with the development of caregiving relationships in dementia care. Therefore, believing the best way to start would be to gather an overview of what current literature offers, in respects to explanations, opinions and perspectives concerning the underlying nature of relationships as a whole.

More specifically, Tom Kitwood's (1993) work and literature revolves around developing a theory towards dementia care. He does this by relating his work to interpersonal models of communication which he then incorporates into the development of a model of communication for individuals living with dementia. He explains how the use of electro-mechanical analogies may help in our understanding of how information processing is restricted as a result of the individual's neurological impairment. Analogies can be used as a formal description of knowledge which joins a set of concepts together, to produce new and sharable knowledge representation about the domain. Kitwood (1993), argues that much of social and psychological research explains communication as being like a radio signal with a transmitter and receiver, where various factors might interfere with the encoding and decoding of the message. Whereas, Kitwood (1993) recognises there are some circumstances where this is an appropriate analogy, he argues it is unhelpful in the complex context of interpersonal communication between a carer and someone living with dementia. In this instance, Kitwood (1993), describes them as the "Morse code model of communication" (Kitwood, 1993. p.54). This kind of theory has been applied to the developments of communication with those living with dementia. It explained how "in any communicative act there is a pre-existing message,

independent of the code; that a code exists, independent of the communicative context; and that the code is understood similarly at some level (even if preconscious), by both the sender and receiver” (Kitwood 1993, p. 55). He appreciates how the approach fails to grasp the idea of personhood. Therefore, when developing a model for dementia care, Kitwood focused his work on symbolic interactionism by drawing on knowledge shaped by our social world. From this he developed the ‘reflective triad’. This was used to explain how communication between two people exists. This reflective triad is used to explain the interpersonal processes in dementia. The Reflective Triad takes form when the “first person makes an action, the second person then interprets the first person’s action then responds. The first person then interprets the second person’s response and reflects upon it” (Kitwood 1993, p. 55).

Kitwood (1993), understands his model has some limitations especially when applying this model to severe dementia as communication becomes unpredictable and complex. More recently, literature is beginning to talk about RCC in dementia care which is based on the work of Kitwood (1993). The concept of RCC is particularly relevant to the current study. Many of the interviews incorporated questions which aimed towards exploring the participant’s views regarding the client-caregiver relationship. Kitwood (1993), highlights how ‘personhood’ still remains possible in those living with severe dementia and believes there are indicators of personhood in everyday situations which can be expressed via expression of pleasure or showing social concern. Again, the current study offers insight into every day situation in dementia care which is discussed in chapter four.

One particular example of more recent literature focusing on the idea of RCC is Brooker, (2007). They talk about the influence relationships have on personhood in dementia care. They conducted a hermeneutical design based on ten cases. They discovered that relationships which sustain personhood were close emotional bonds between family carer and individuals with dementia and professional relationships between caregivers and individuals with dementia. Smebye et al., (2013, cited in Brooker, 2007), talks about developing a contemporary classification of person-centred care which highlights four crucial elements,

bringing personhood to the foreground. These elements are labelled with the acronym (*VIPS*). The 'V' represent a value base that represents the value of all human lives regardless of age or cognitive ability. The 'I' represents an individual approach which pays attention to a person's uniqueness. The 'P' concerns an understanding of the world from the perspective of all the dementia patients. Finally, the 'S' represents a way of providing a social environment that supports psychological needs. (Smebye et al. 2013).

These elements offer a straightforward classification of PCC which can be applied to all cases of dementia and even later/end stages of dementia. However, the extent to which health care professionals are aware of this research could be more fully explored, in order to assess its effectiveness and whether it is useful in practice.

Additionally, Clissett et al. (2012) uses Kitwood's (1993) work as a framework to explore current approaches to care in an acute setting. They aimed to see whether there was potential to enhance personhood in older adults with dementia. This was done by exploring the current experiences of people with dementia, family and HCAs during hospitalisation. Clissett et al. (2012) found that despite examples of good practice, HCPs in acute settings were unable to grasp the opportunities to maintain personhood for people living with dementia. This was due to factors such as ambiguity in policy and despite the consensus in the desire to be '*person-centred*', varied interpretations of the person-centred approach still remain.

Furthermore, Nolan et al. (2006), argued that 'person-centred care' needs to be expanded to 'relationship-centred care', therefore, they proposed the 'senses framework' to aid in understanding the network of relationships involved. He expresses how there is a triangle of relationships between the person living with dementia, the family and the care home staff members. Nolan et al. (2006), highlight six senses which are key for relationships to be mutually satisfying for all involved. These six senses are seen as prerequisites for good relationships with in the context of care and service delivery. These six senses are illustrated in the figure below;

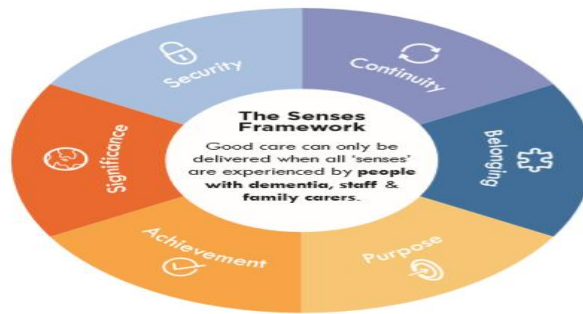


Figure 1- The Senses Framework

(Sheffield T. u., 2018).

Nolan et al. (2006) argue that implementation of this framework can help ground practice. While placing the relationship between the caregiver and resident with dementia at the centre. They believe this type of practice allows for care homes to grow and flourish. Again, its use in practice needs to be more clearly articulated. By exploring how this information is being processed by HCPs. Also by exploring the extent to which type of HCPs would benefit. For instance, is it made available to Trainee HCAs who could perhaps benefit from such knowledge? An exploration into what research is made available to trainee staff, would be beneficial to practice, as it sets a foundation of expectations and person-centred care principles in the most vital stages of training.

The term 'relationship-centred care' was originated by Tresolini and the Pew-Fetzer Task Force (1994). This was a result of an extensive review of the adequacy of modern day Health Care systems in the U.S.A (Nolan et al. 2006). RCC can be defined as care in which all participants appreciate the importance of their relationships with one another (Breach et al. 2006). It is recommended that illness, care and healing processes transpire in relationship-relationships of an individual with self and with others.

RCC is a framework which can provide context for numerous functions and activities in practice. For instance: Breach et al. (2006), explain how within relationships, we exchange information, share resources, arrive at diagnosis, select treatments and measure the outcome

of care. They explain how all interactions within health care are facilitated by the quality of manifold relationships that connect patients, clinician, team, organisations, and community.

Breach et al. (2006) explains how RCC is built upon four key principles. These are as follows;

- *Relationships in health care ought to include dimensions of personhood as well as roles.*

This principle highlights how both the patient and the clinician are unique individuals possessing their own set of experiences, values, and perceptions. As a result, RCC expresses the need for clinicians to remain aware of their own emotions, reactions, and biases whilst simultaneously monitoring their own behaviour in light of this awareness (Breach et al. 2006).

- *Effect and emotion are important components of relationships in health care.*

This principle requires an understanding of the central importance of effect and emotion in developing, sustaining and terminating relationships. RCC explains how when clinicians are emotionally present, the patient is allowed to feel emotionally supported. This principle encourages clinicians to have a degree of empathy with the patients, because empathy has the potential to aid the patients experience and express their emotions in return, allowing the clinician to better understand the needs of the patient (Breach et al. 2006).

- *All health care relationships occur in the context of Reciprocal Influence.*

This relates to an understanding of the fact that health, and health related actions do not occur in isolation but occur in relation to one another in time, space and content. By knowing patients, RCC encourages clinicians to grow as a result. The idea of reciprocal influence means actions, values and principles are influenced by others. For example, health care relationships are dependent on the values and principles displayed by organisation and therefore influence how a HCP views relationships in health care (Breach et al. 2006).

- *RRC has a Moral Foundation.*

This principle operates on the belief that the forming and maintaining of relationships in health care is morally valuable for a plethora of reasons. For example; genuine relationships are

morally desirable as it is through these relationships that clinicians are able to develop interest towards patients and invest themselves in order to assist others and to be fulfilled by doing so (Breach et al. 2006). Breach et al. (2006) articulates the importance of relationships in health care but believes there are limitations in how these principles are practically addressed.

Dewar (2013) describes a model of compassionate relationship-centred care (see figure 2). This might be more suitable to the current study, as it incorporates various dimensions essential to the practical elements of implementing this model. It is argued that these elements will improve relationships in health care.

Essential to the current research, is the model of compassionate relationship-centred care is aimed mainly at older people in acute hospital settings. This also includes those living with dementia therefore making it equally appropriate. It is appropriate because the current research is looking to focus on relationships in residential dementia care. Dewar (2013), model actively involves older people, staff and relatives as a way of identifying strategies to promote such care across practice and educational environments. This links to the current study as the method involves communication with HCPs, via interviews, which incorporated some questions that involve direction towards opinions of how the future relationships in health care looks.

Dewar and Nolan (2013), proposed a new practice model which aims to clarify the meaning of compassion and how it can be accomplished in practice with patients and staff. The key parts of the model articulate the idea of caring conversations. These represent an advance highly skilful forms of relational practice. They identified the seven C's in this model. They created appreciative caring conversations with the aim of introducing and articulating strategies, which enhance compassionate care for older people. This is an idea based on the belief that asking questions and engaging in appreciative caring conversations creates connections between people.

These seven concepts are based on three core ideas which are crucial to understanding and developing the caring conversations. Figure 2, illustrates their model with the seven Cs around the outer circle and the three core ideas in the middle (Dewar & Nolan, 2013. p.9).

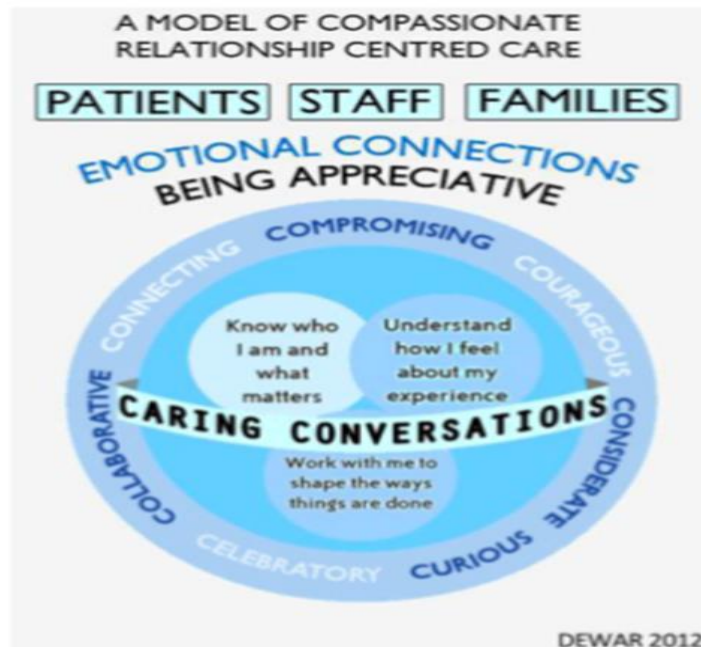


Figure 2- Dewar & Nolan's (2013) model of caring conversations.

Dewar (2013), based the seven C's on a relational awareness of what is involved in the staff-client relationship, which in turn could aid in better understanding of patient's needs. Dewar (2013), describes this as; "making a connection and clicking, knowing the little things that matter and not assuming how people want to be cared for" (Dewar, 2013, p.4). This helps to develop skills to make connections with individuals. This could aid in the development of relationships in the busy world of practice (Dewar et al. 2013).

Furthermore, Dewar (2013) highlights how previous literature identifies the fact that people often value the interpersonal components which are present in caring, and which contribute to the development of professional caring relationships by addressing how these particular models creates questions concerning how to encourage caregivers to embrace a relational and responsive model.

Dewar (2013), discusses how these appreciative approaches can provide an increased understanding of the complexity of delivering health care. Ultimately, appreciating how the

practical use of the seven C's model adds to a body of knowledge regarding the practice of compassionate care.

As a result, Dewar et al. (2013) produced the Leadership in Compassionate Care Programme which aims to develop a transferable programme to be used in health care practice and to embed compassionate care in practice. They used an appreciative enquiry to learn about other people's experiences; which is an approach focusing on utilising existing strengths, achievements and successes of health care providers. The use of this method is reported to motivate and empower stakeholders to change their life, situation, or organisation. Ultimately, appreciative enquiry relies on the value and importance of relationship to learning and growth (Robert et al. 2015).

Furthermore, the use of emotional touch-points is communicated in great detail in Dewar's research, explaining how this can be a way of hearing the voices of patients and families in care facilities. Dewar et al. (2010) explains how the use of emotional touch-points can help to emotionally engage with patients and families. This is done to understand the experience of health care on a deeper level. By highlighting a realistic way in which patients and families can be involved in the service design to aid in uncovering aspects of compassionate caring practice which are not easy to define. Dewar et al. (2010) provides a useful insight which can be linked to the aims of my current research topic. As Dewar's model relates to the care of older people in care settings by providing a practical model which is designed to be logical and straightforward. It appears appropriate to attempt to use such a model in a dementia setting. To support this claim, she conducted an appreciative inquiry to confirm that the caring conversations framework has applicability beyond the hospital setting to a care home. The outcome of this study resulted in the development of an educational programme to enhance caring conversations in practice (Dewar, 2017).

However, it is perhaps limited to cases such as final stage dementia, or in cases whereby factors such as aggressive behaviour and uncooperative patients are involved. This is vital in

residential dementia care as such factors are experienced by HCPs daily. Therefore, a way of accounting for such factors would be to consider the real life applicability of the framework. Following discussions of Dewar's work, I would now like to introduce a corresponding area in the literature. This is concerned with the development of relationships in care homes and the types of relationships involved when practicing care.

Wilson (2009), discussed the development of personal relationships in care homes and highlighted how such relationships can be an integral part of living, working and visiting in care facilities, stating how infrequently research has made relationships their main focus of enquiry, with limited research into the perspectives of family, residents and staff. His findings revealed three types of relationships in his data collection across three care homes.

The first being 'pragmatic relationships' (Wilson, 2009. p. 10) which centre on the practical nature of caring. This was developed via communications directly concerned with care tasks. The second being 'personal' and 'responsive' which he defines as understanding the resident as a person. This relationship develops through communication that revolves around social conversations with family and the residents themselves. The third being 'reciprocal' which depicts a negotiation and compromise where the needs of the staff, family and residents were considered in the context of a trusting relationship.

Overall, Wilson (2009) highlights how personal relationships are essential to residents, family and staff in order to have positive experiences of life within a care home for all involved. Thus suggesting that the way in which staff members approach the delivery of care, ultimately influences the type of relationships that develop in care homes. The article can assist in an increased understanding of the types of relationships which can be developed in care homes, and how these relationships come to exist with insight into the relationship network surrounding particular individuals living in care homes. The article may not be specifically related to dementia care, however, an understanding of what previous literature suggests about the development of relationships in care can be useful when exploring the experience

of HCPs and the perceptions of client and caregiver relationships in residential dementia care. As the current research focuses on the 'lived experience' of these particular relationships, there may be limitations in terms of explaining the execution of these relationship types in practice. Therefore, questions arise concerning how much of this information is being communicated within day to day health care practice and how this applies to a typical working day in a health care setting.

Furthermore, it does not account for factors which can hinder relationships. Moody et al. (2006) notes how the practicalities of developing person-centred practice could impact negatively on staff morale in cases where there were already low staffing levels. Hewitt-Taylor (2015), agrees that this could reduce people's motivation to develop their practice, explaining how in order to develop this type of practice, practitioners need to subscribe to a person-centred ethos and commit to making it happen by creating a work place culture and norm.

Although, Dewar's (2010, 2012, 2013) research does highlight these concerns to a certain extent, by paying attention to the relationships in dementia care. There is further literature which relates to the discussed ideas. For instance, Goodrich and Cornwell (2008), produced a point of care review paper named seeing the person in the patient. The paper stressed the importance of paying attention to the 'how' as well as the 'what' of clinical treatment in health care, highlighting how policy makers and government have made patient experience a national policy. The authors also cite the Department of Health (2008) in their introduction to the review paper stating that improving patient experience is central to high quality care for all. They agree with paying attention to why patient experience is so important. As it aids the understanding of how patients are experiencing care. Ultimately, improving the standards made to quality of care. Goodrich and Cornwell (2008), further argue how patient experience is justified clinically in terms of value for money. If we are to link this to the aims of the current research, which is to deepen our understanding of the HCP's point of view, one can see the importance of researching in a way which understands people's experiences. Obviously, in this instance Goodrich and Cornwell (2008) are focusing on the patient experience in English

hospitals, however, you can see how this could be more associated with the experience of HCPs in residential dementia care.

Goodrich and Cornwall (2008), also attempt to make sense of the term 'person-centred care'; paying particular attention to matters concerning the translation of research language and policy into the everyday language of staff in hospitals. They explain how the language we use shapes policy, the care given and the understanding of patient's experience of the care provided. Their field work found, that HCPs in the field, preferred using ordinary, human words for care such as; respect, dignity, sensitive and understanding. However, the phrase 'seeing the person in the patient' could bode well with their participants. They discussed how their participants did not appear to be aware of or influenced by research literature or policy. Therefore, this suggests that much of the terminology used in research and policy are experienced as impositions from the outside. This is useful to consider when discussing the findings of the current research.

Sanderson and Lewis (2012: 2011), produced a practical guide to delivering personalisation in health and social care. They explain how we need to understand person-centred thinking, so we can demonstrate personalisation in action/practice and support for individuals. The guide also provided some insights into the origins of person-centred thinking tools and from where they originated. For example, the guide explained how these tools developed from leaders in the inclusion movement, such as Beth Mounts Relationship cycle. The guide describes how for people to have real choice and control over their lives and services, those implementing the care/support need to understand:

- What is important to people, so that services and supporter are built around what matters to them as individuals, instead of people being seen as a label, condition, or, stereotype.
- How, when, and where people want support or services delivered, rather than a standard 'one size fits all' approach.
- How people communicate the way in which they want their services to be personalised. If the person does not use words, there needs to be clear ways to make these decisions and judgements and to record them.

Sanderson and Lewis (2012: 2011), then goes through each person-centred thinking tools and addresses ways to achieve this. For instance, person-centred reviews which act as a means of transforming statutory reviews in services to create person-centred actions. Another example being, the use of person-centred planning which focuses on the individual and creating positive outcomes. Although the guide is generic to all health and social care, the principles can be relevant and useful when considering relationships in dementia care as personalisation comes with developing relationships.

Hewitt-Taylor (2015), discussed the development of person-centred practice, covering a broad range of contents relating to how person-centred practice can be understood and developed. He explored factors contributing to what is currently hindering the development of person centeredness. For example: both human and material resources can contribute to the development of person-centred practice, such as, structures and organisational policies, but also individual values, priorities, and work place cultures. Moody et al. (2006) would also agree as they explain how poor staffing levels make the practicalities of developing person-centred practice difficult. This in turn reduces staff morale, therefore, reducing the chances of building a work place culture that permits a person-centred ethos. As a result, these studies point to a need to improve and pay attention to the resources readily available to health care providers and evaluate the extent to which person-centred practice is affected by lack of resources in health care.

Relationships and dementia

In this section of the literature review, I would like to turn my attention to a more focused area of literature. This is particularly relevant to the current aims of this master's project. This is because it demonstrates how relationships and dementia relate to one another specifically.

Williams et al. (1999), questioned whether we can create a therapeutic relationship with nursing home residents who are in the later stages of Alzheimer's disease. They explain how research has begun to focus on the emotional impact of dementia on the individual in the later stages. Ultimately, they discuss how their findings aim to challenge the assumption that therapeutic work with moderate or severe dementia patients is impossible. When discussing future research, they explain how their results were dependent on verbal aspects of interaction, indicating how there is room to research these elements further.

With this in mind, Blass (2007), explore how the lack of patient participation can affect the establishment of the physician-patient relationship. He explains how when a patients verbal abilities are greatly impaired, discussions regarding their care usually take place without their presence. Leaving that person at risk of objectification, especially if a patient is brought to them with misleading pretences. He explains how the medical care of patients living with dementia can place unique demands on the physician-patient relationship. Therefore, explaining how the scope of the physician-patient relationship is usually extended to include family members and caregivers. Highlighting the importance of models explained above in part one of the literature review, such as, person-centred care and relationship-centred care.

Baldwin (2006), proposed an interesting way of looking at understanding the workings of relationships. He explains how the formation of relationships operate in a three way process. Initially, there are two individuals, but for the relationship to occur there requires a level of '*connection*' between the two. He emphasises how in the absence of this '*connection*' remains two separate perspectives. This '*connection*' can be a shared understanding of each other's perspectives and also a level of empathy between the two individuals. If we were to apply these ideas to relationships between HCPs and those living with dementia, you may notice that the connection between the two individuals may soon become a network of connections/relationships between amongst many perspectives depending on the individual's circumstances. For instance; in residential dementia care; the network of relationships is not just between the care-giver and the resident, you also have the families, doctors and other

external individuals involved. Jacobson et al. (2000), recognises that HCPs are central to quality of life, with the relationships between resident and care-providers being a central feature of this quality.

Savundranayagam et al. (2007), explores communication and dementia by looking at staffs perspectives of communicational strategies. The study used scripted staff-resident conversations to examine the differences in communication strategies. They explain how participants rated staff who incorporated personhood more favourable than those who used more directive language. Their findings suggested how the use of language which includes and validates residents, staff members who showed these factors were seen as more respectful and capable with interactions with the residents. Furthermore, they also suggest that poor communication with individuals with dementia is usually associated with conflict in relationships, social isolation, which ultimately increases burden and stress for caregivers along with other consequences. Evidently, one can see how communication poses as a vital factor contributing the overall relationship between a resident living with dementia and the care-giver.

More recently, Quinn et al. (2009), examined both pre-caregiving and current relationship quality and concluded that an understanding of the role of relationship quality could potentially aid in the development of more efficient interventions for caregivers. The study revealed how some care-givers were perceiving differences between current and pre-caregiving relationship quality and that these factors were associated with overall well-being of the care-givers. In respects to the current study, this piece of literature is particularly interesting to consider, when looking at relationships in residential dementia care.

Morality and ethics in caring

Moral theories and ethical decisions are often a topic of debate in care practices. Moral theories are based on structures of thought and belief that aid our decision regarding what is

good and what is bad. However, ethical decisions are described as decisions regarding what it might be right or wrong to do. For instance, consequentialism explains the idea of whether you wish to understand if an action is right or wrong, the outcome of the action needs to be assessed. Hughes and Baldwin (2006), pointed out how looking at the consequences and what follows, takes the focus off the action itself. Alternatively, deontological (duty-based) ethics suggest how if you wish to know whether to do something, you should ask “is it my duty to do this?” as opposed to “what will be the consequences?” (Hudges & Baldwin, 2006. p.18).

HCPs would currently understand this idea as ‘duty of care’, meaning, as a care provider, we have a duty of care to act in the best interest of the residents. Hughes and Baldwin (2006), contextualized the idea of deontology; by suggesting how once you become responsible for somebody, you have to care for that individual, not a result of consequences, but as it is your duty to do so. They aimed to address the problem with choosing between ethical theories through ‘principlism’. They believe by basing one’s choices on certain common principles one will always do the right thing. These are often referred to as the four principles of medical practice;

1. Justice - suggesting individuals should be treated equally and fairly.
 2. Autonomy -meaning individuals should have the decision of what they wish to happen or wish to be done.
 3. Non- Maleficence - meaning we should avoid causing harm to anyone.
 4. Beneficence - meaning we should aim to do well to those we care for
- (Beauchamp & Childress, 2001, cited in, Hughes & Baldwin 2006)

With my current and personal understanding of what is expected as a HCA, the actual real life application of these theories can be somewhat clouded in the busy world of health care, especially when working with individuals living with dementia. For example, cases where there are emergencies and you have to focus all your attention, attending to that person’s immediate needs at the time, whilst having to be aware that you have to also ensure you attend to the needs and safety of everyone else on the unit. Instances such as these, when staff and resources may be limited, place a great deal of pressure on HCPs to consider each principle

and make the correct decision in the moment and consider all possible consequences. Though these theories offer some support and guidance in decision making in practice, they do not dictate what to do in the first place. They merely offer a description as to why you choose to act in a particular way. Therefore, making the application of these theories complicated. This is because each individual has their own set of personal principles, meaning peoples decisions will always vary. As a result, differences of opinion will always exists, inevitably, opening doors to moral dilemmas between health care staff.

A further area of morality and ethics in caring, which specifically relates to dementia care, is the discussion of truth-telling. The decision to tell the truth or to withhold information can be seen as a way of showing concern for the person living with dementia. For example, Hughes and Baldwin (2006), explain how cases where perhaps the family might not wish to tell their mother/father that they have a diagnosis of dementia as they do not want to burden them with the stress of it, which places some stress on their relationships. Another example could look like an individual with dementia, continually asking were there husband is, despite him perhaps dying many years ago. Health care staff perhaps use therapeutic lies in this instance as a means on settling that person, rather than continually explaining to that person that their husband has passed away, which will upset them every time. In cases like these therapeutic lies are perhaps considered helpful in managing symptoms of dementia and comforting that person.

The aims of this research;

From my review of the literature, it is clear that morality and ethics in caring, the practicalities of maintaining relationships in care and addressing person centred care in practice are some of the key issues for understanding experiences of care in dementia home settings. The aims of this project are therefore as follows;

- To gain a rich understanding of Health Care Professionals perceptions of client and caregiver relationships in residential dementia care.

- To understand how Health Care Professionals lived experience of working in dementia care environments impacts on professional caring relationships between the resident and caregiver.

Chapter Summary

As a Health Care Professional, it is useful to understand the types of relationships a resident has prior to coming into residential care. This could potentially affect the way in which care is delivered when the resident arrives into care. As a result, the current study will explore HCPs experiences and perceptions in order to deepen our understanding of client- caregiver relationships in dementia care.

This particular interest to conduct an Interpretative Phenomenological Analysis on the 'relational aspects' of dementia care stemmed from my previous experience as a HCA, combined with a passion to improve the quality of life for those currently living with dementia. It is important to recognise how caring for those living with dementia can be challenging and overwhelming at times, as no two days are the same. Each day brings new obstacles as a caregiver, having to adapt to fluctuating levels of ability and patterns of behaviour.

The literature review has demonstrated some direction towards an understanding that relationships do play a vital role within dementia care, therefore, highlighting my choice to focus on relationships. The literature has established how relationships are viewed and explored, also considering how they operate on an interpersonal level. Furthermore, it has highlighted how communication plays a role in building relationships in care, whilst emphasising how lack of patient participation can affect relationships. This is particularly relevant when considering relationships in dementia care, when communication can be limited due to the symptoms of dementia. The literature review also makes sense of person-centred practice and explores how the organisations play a role in the quality of relationships in dementia care.

Whereas the current study and its chosen method, will offer a deeper exploration into how HCPs make sense of relationships within a current dementia care environment. In particular, offering an insight into the 'lived experience' of the phenomena, from the perspective of the HCPs themselves. As the participants in this study vary in both experience and age, this research also attempts to account for such factors. By doing so, the research offers a deeper scope into how these factors are linked. This can be witnessed in the participant's accounts of their personal experience. The current study offers insight into how the practical factors of the job role can influence relationships. This can be understood by the way the participants express their thoughts and feelings during the interviews. These types of experiences are unique to residential dementia care and they are specific and meaningful to each individual. The use of IPA aids in achieving this, when compared to previous research literature.

The following chapter will introduce the chosen methodology for this particular research project. In this case, the chosen method being, Interpretative Phenomenological Analysis. The use of this particular method, should aid in highlighting the current gap in research literature in the field of relationships in dementia care. One hopes that by using this method, we are able to answer for the gaps in the literature, concerning the lived experience of relationships in dementia care.

The following chapter aims to outline and justify the methodology and methods chosen to utilise throughout this research, incorporating an explanation of the process of analysis and a description of procedures taken, whilst considering the ethical considerations associated with carrying out this research.

Phenomenology and Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis is a qualitative approach concerned with the comprehensive examination of individuals' lived experience, formally developed by Jonathan A. Smith in 1996. Smith (2011), explains how IPA recognises there is no direct route to experience and that research is concerned with attempting to be 'experience close' rather than 'experience far'. Interpretative Phenomenological Analysis is an inductive approach, a 'bottom-up' outlook on data as opposed to a 'top-down', meaning the approach to data tends to be unstructured and exploratory allowing the data to lead to a result as opposed to constructing an experiment to answer questions. This type of qualitative research method does not test a hypothesis and avoids all prior assumptions. For the purpose of this paper, I will be exploring how HCPs make sense of the experience of relationships in dementia care using an inductive approach to explore patterns, meanings, and themes that arise in the data.

Historically, phenomenology stemmed from a reaction to Positivism whereby the discourses of the physical sciences were applied to all forms of human inquiry. Positivism emphasises the given in the interpretation of knowledge, meaning all knowledge, according to positivistic philosophy in general, is based on the sense-given as the real source of knowledge (Sinha, 1963). The theory of Positivism is concerned with the application of method resulting in hard facts. Following general rules and hypothesis testing resulting in quantitative data to identify causal explanations and laws which will explain behaviour. Whereas, phenomenology questions how individuals make sense of the world surrounding them and suggests that

human action is meaningful, also, incorporating empathy towards the research sample and therefore do not apply or test a hypothesis. The term 'positivism' is not considered appropriate for contemporary research in this tradition as it is not restricted to the 'sense-given'.

Etymologically, the phrase 'phenomenon' is described as a fact or situation that is observed to exist or happen. Heidegger (2010), suggests phenomenology means to 'let what shows itself be seen from itself, just as it shows itself from itself. Therefore, phenomenology is said to be a philosophic method for questioning, as opposed to a method for answering or discovering determinate conclusions, allowing for the researcher to access the meaning of phenomena and events in their singularity (Van Manen, 2016). Similarly, Edmund Husserl, the founder of phenomenology, believed that experimental scientific research could not be used as a means to study all human phenomena and aimed to establish a rigorous science that found truth in the lived experience (Roberts, 2019).

Edmund Husserl (1931) attempts to capture the concept of expressing how the world is experienced through conscious acts. The phrase, "returning to the things themselves" (Chase, 2011. p.115) stems from worries regarding philosophical and metaphysical positions losing touch with what Husserl called the lifeworld (Chase, 2011. p.116). Therefore meaning that a "phenomenologist should not start with a theory (metaphysics), then turn to experience to confirm that theory or hypothesis" (Chase, 2011. p.117).

Phenomenology describes the way in which things appear to us in experience, suggesting how the reality we live in is an experiential one, experienced in the form of practical engagements with people and stimuli in the world and this concept is considered meaningful to each individual in some way. Husserl explains how the basis for meaning is a determinate relationship concerning an act of consciousness and its object. Similarly, Husserl describes how the 'outer world' of things and events are experienced through a sequence of adumbrations, profiles or aspects. Therefore, an individual's perception has a partial and perspectival quality which is appreciated as a function of our spatial and relational place in the

world. Furthermore, he highlights how our sense of what happens within the world is a product of one's positions and perspective in connection to the object that we observe.

In the later work of Heidegger and Merleau-Ponty, the distinction between the perception of the inner and outer world developed towards more of a focus on the inevitably situated nature of human experience (Larkin, 2019). Merleau-Ponty offers the perspective of a witness of behaviour as being an alternative to introspection as a mode of finding meaning in the lived experience. As a result, Churchill (2012. p. 2) elaborates on this idea of having a witness of behaviour. He discusses how the “second-person perspective itself emerges when we initially engage the other person as you, which is said to occur at the moment that we first address the other, whether as a speaking or a non-speaking subject”. He highlights how the second person perspective can illuminate the ways in which we as observers have a direct access to the meaning of other people’s experiences without having to go through the intermediary of first person reports. He believes this is important in cases where the other person is unable to speak for themselves therefore, the second person perspective is a vital tool in all health care contexts. Churchill (2012. p. 5) gives examples of the implications of the second person perceptivity for health care professionals, explaining how “the aptitude that we all have as living persons to engage directly with others, to perceive meaning directly in human expression, and to be able to grasp intuitively what the other needs from us”. This can be linked to the current study of relationships in dementia care as we witness examples of this in the participants’ accounts. For example, the accounts offer insight into experiences concerning how HCPs naturally interact and tend to the needs of the residents.

Similarly, Finlay (2014), explains how the challenge for researchers lies in the ability to push beyond what we already know from experience or via established knowledge. Finlay (2014) speaks about a ‘phenomenological attitude’ meaning to break away from our own natural attitude and establish a fresh way to remain open to new understandings.

Phenomenology, Ideography, and Hermeneutics can be considered the main cornerstones associated with the development of IPA. The understanding of experience requires a process of interaction and engagement on behalf of both the researcher and participant and it is from this one that can link IPA to a Hermeneutic perspective. The process of IPA engages in a 'double hermeneutic' which involves the researcher attempting to make sense of the participant making sense of a particular phenomenon (Smith, 2011). Van Manen (2016, p.26), explains how "hermeneutic means that reflecting on experience must aim for discursive language and sensitive interpretive devices which make phenomenological analysis, explication, and descriptions possible".

Finally, IPA holds an idiographic commitment to the in-depth analysis of personal experience on a case-by-case basis, meaning each individual experience has its own presence with an articulation of both convergence and divergence between each case in the sample (Smith, 2017). As IPA studies tend to be conducted using a small sample, Smith and Osborne (2008) explain how such detailed examinations of individuals are rare in psychology. Therefore, studies express how a particular experience is lived can have an important contribution to make towards the discipline.

This paper is particularly interested in HCP's experiences of caregiving relationships in dementia care. This is a phenomenological question which would be best addressed using a qualitative method of inquiry. This research considers the phenomenology of caregiving relationships and investigates how health care professionals make sense of this on a case by case basis. The use of IPA allows the claims and concerns of health care professionals to be fully explored whilst offering insight to more personal aspects of the phenomena which are meaningful to that person. For instance, the themes generated from the participant's accounts reveal something about HCP's present stance towards relationships in dementia care and the use of IPA aids in illuminating this by allowing the researcher to make sense of their experience via the process of interpretation.

For the purpose of this paper, I will be exploring how HCPs make sense of the experience of relationships in dementia care using an inductive approach to explore patterns, meanings and themes that arise in the data.

Interpretive Phenomenological Analysis aims to explore the 'lived experience' of a particular phenomenon, learning from the insights of experts; the research participant themselves (Smith, 1996). Participants are experts on their own experiences, therefore, IPA allows researchers to utilise their expertise by gaining an understanding of their thoughts, feelings, and commitments. This happens through telling their own stories and exploring their perspective on a particular phenomenon via the process of interpretation. Interpretations are then made possible in respects to how individuals make sense of their personal and social world. This method is specifically appropriate in health care research as IPA suit topics such as; health, social, and clinical psychology where there is an underlying need to decipher how individuals perceive and comprehend significant events in their lives (Lyons & Coyle, 2007).

With this in mind, for the purpose of this research, I will be adopting a person-centred and holistic perspective to aid in illuminating the experience of relationships in dementia care. Holloway et al. (2016) explains how the use of this perspective, particularly in health care research, by nurses and other health researchers gain knowledge and insight about human beings – whether it be patients, colleagues, or, other professionals. They highlight how using qualitative research allows researchers to tune in with the nature of the phenomena by examining; emotions, perceptions, and actions. Which in turn, allows the findings to translate to clinical practice.

I aimed to generate a sample which reflected the aims of this particular research. Therefore, I recruited HCPs who have had experience with working on a residential dementia unit. Age, gender, and length of experience was not restricted when gathering my desired sample as I believed it would be useful to incorporate a range of perspectives – irrespective of age, gender, and length of experience. I believed such factors which differentiated participants, i.e., age and experience would offer some interesting discussion when it came to analysing participant's responses. All participants were from a white British background. Purposive sampling was employed to recruit participants from a residential dementia unit that provides long term health care. Potential participants were identified by myself, after discussing the idea for research with potential participants, those interested were introduced to the study via the information sheet provided by myself prior to interview. The HCPs informed me of their availability for interview and a schedule was produced as a result; following confirmation of interview date, time and location.

Participants

Five participants (one male and four female) were interviewed once and they are referred to in this research by the pseudonyms Stacey, Tammy, Masie, Catherine and Samuel. All participants involved in this research came from a health care environment and all currently work in residential care facilities, particularly specialised in caring for residents with Alzheimer's disease. All Participants had varying levels of experience and age. To illustrate, the table below depicts a summary of the participants who took part in the research.

Table 2 – Table of Participants

| PARTICIPANT | JOB TITLE | YEARS OF EXPERIENCE |
|-------------|------------------------------|---------------------|
| STACEY | Manager | 25 |
| TAMMY | Health Care Assistant | 4 |
| CATHERINE | Health Care Assistant | 3.5 |
| MASIE | Senior Health Care Assistant | 24 |
| SAMUEL | Senior Health Care Assistant | 11 |

Data collection

In order to meet the research aims, five semi structured interviews were conducted via a face to face interview as it allowed opportunity to collect a rich data set from all participants. As the interviews were semi structured, I was able to be flexible with the questions I asked, which in turn, allowed the participants to discuss topics which they felt were most important, but also keeping some stability and structure. The interviews were then audio-recorded, and took place in the environment of their choice and at a time and place which was most convenient for the participant. Prior to conducting the interviews, the plan was to use an environment that was quiet and relaxed in order to allow the participant to feel comfortable to speak openly about their experiences. However, throughout the process, this became quite difficult to achieve given the busy schedules of the HCPs who agreed to take part in the research. Many of the interviews took place during their shifts. This was the only possible opportunity available to speak to the participants. The interviews ranged from 30 to 50 minutes in length.

Each participant agreed and signed the consent forms and were asked if they were comfortable with everything prior to interview beginning (See Appendix A). The interviews were digitally recorded and at the end participants were thanked for their participation in the research. All participants were informed they could still ask questions about the research despite the interview process being completed. The interview data collected was anonymised by removing material that could identify them: for example, when the recordings were stored on the researcher's personal computer they were numbered from 1 to 5 as opposed to using names in order to protect their personal identity. When conducting the analysis pseudonyms were created to use instead of numbers, to keep the accounts more human and personal while protecting identities.

The interviews were organised to fit around the participants' needs, considering most participants often juggle a combination of work, family and other commitments. As a result, prior to interview, participants were offered a choice in arranging the interview in a way which best suited them. For example, Peters et al. (2015), explains how offering interviews using other routes such as Skype allows for more flexibility in terms of time and location. Which also ensures privacy and in a location where they may have been less likely to have distractions. Although potential technical difficulties must be taken into account. In this case, my participants were comfortable with having the interviews take place in the workplace during a time in the shift that was less likely to have distractions. Despite the issues discussed in previous sections, in the end this worked out well. It allowed the participants to feel safe, but was also convenient as they did not have to travel to a different location, out of the way of their working day.

Procedure

The form of data collection chosen was Semi-structured interviews. Semi-structured interviews are considered flexible, intelligible, and are said to be capable of disclosing

important information, uncovering hidden facets of human and organisational behaviour. As a result of its basis in human conversation, which is particularly relevant to the nature of relationships in dementia care, semi structured interviews allow the researcher to modify the style, pace and ordering of questions to evoke the fullest responses from the participants (Peters & Halcomb, 2014). The current research questions were designed to capture the essence of the participants experience and perception of caregiving relationships in dementia care; with each interview lasting approximately 60 minutes each. (See Appendix B).

King and Horrocks (2010), discuss how texts on qualitative interviewing highlight the importance of avoiding leading questions during interview. As the questions were designed and developed by myself, I had to be aware of my own pre-conceptions as I too, have the experience of working in a dementia care setting and the participants also knew myself on a personal level. For example, when I originally developed the interview schedule some of my questions gave some insight prior to the participant answering the questions, this could have potentially influenced their response. Therefore, careful revision of these questions took place prior to the actual conducting of the interviews. Similarly, I also asked the participants in the sessions to answer the questions in as much detail as they could. They were asked to consider me as someone who had no previous experience or knowledge of dementia care. Furthermore, the interviewing style and techniques used were based around basic counselling theory and practice as I believe this would create a more comfortable environment and 'safe space' for the participant to share their experience and freely express themselves.

The interviews were conducted in the participant's place of work. In this case, a residential dementia home. They took place at a time when the shift was particularly quiet and lasted approximately 40 to 50 minutes. I occasionally stopped the recording if a particular task came up during the shift. All interviews took place in this way.

As previously discussed, Interpretative Phenomenological Analysis was used to analyse the data. This involves making interpretations from the participant's accounts through the lens of phenomenological theory. This was achieved via careful revision of the interview transcripts and familiarising myself with the data. Each transcript was read and re-read making annotations about the participant's experience along the way, down the left hand margin of the transcript. For example, annotations were made based on the participant's thoughts and feelings, including comments of what feelings could represent. These annotations were then grouped into themes and clusters, ultimately generating a table of themes consisting of four superordinate themes which we discuss in more detail in chapter four.

One important factor to consider when analysing the interview data is the process of reflexivity (Ben-Ari, 2011). The researcher is expected to have the capability to manoeuvre between becoming mentally involved and stepping away from the experience. This can be achieved by maintaining an awareness of my own sensitivities when analysing the data collected. I recognised how this may affect my interpretation of the data and tried to keep a conscious thought of this when making interpretations. In order to avoid presuppositions that may influence my interpretation of a participant's response, I attempted to retain an impartial mind-set when looking at sensitive data.

Written reports of my own experience in health care helped me develop further perspectives and allow me to bracket my own perspective from others. This was achieved by expressing my experience in one focused account. However, it is important to acknowledge the impracticalities of remaining hermeneutically grounded within the data. This is because it is impossible to remove our own past experiences. Smith et al. (2009) agrees that an element of reflexivity is vital on behalf of the researcher during the process of interpretation. These

reflective accounts aim to ensure robustness while practicing IPA methodology. They also highlight how the researcher's history and personal interests clarify the motivations for study, and allows the researcher to understand their role as an interpreter (Tobin & Begley, 2004).

Following transcription, each individual transcript was analysed using interpretative phenomenological analysis (Smith et al. 2009). This particular method of analysis was used to highlight the participant's initial perceptions and follow their process of making sense of the experience of relationships in dementia care. All transcripts were read and re-read very carefully on number of occasions to allow myself to become hermeneutically grounded in the data and its content. For instance, the process of dwelling-analysis was used as an attempt to immerse oneself in the data. This highlighted by allowing room for the phenomena to unravel itself. This was achieved by empathetically joining with the participant's accounts by dwelling systematically with the data allowing time for implicit, layered meaning to come forward (Finlay, 2014).

Smith (2009), explains how the interpreter's account of the data should be a credible one. To support this statement, Yardley (2017), discusses how good qualitative research requires a degree of sensitivity towards the data. This can be achieved by carefully generating meaning from the participants. Rigour can therefore be demonstrated through in-depth engagement with the phenomena and a detailed, in-depth analysis. Rigour is important in qualitative studies as it is the means by which a researcher demonstrates integrity and competence (Tobin & Begley 2004). Yardley (2017) explains how transparency is a key element of phenomenological research meaning that the reader should be able to clearly see how interpretations have derived from the data. To account for this, the transcripts were annotated with one column included on the left to demonstrate the researcher's interpretations of the data. Whilst re-reading the data, efforts were made to pick up on the participants thoughts and feelings in an attempt to search for meaning in the data and capture the essence of the experience of 'relationships' in dementia care.

Kacprzak (2017), agrees with the importance of sensitivity to context, explaining how the reader should be able to learn something about both the important generic themes in the analysis and the lives of the participants who have told the stories. Each re-reading provoked and expanded new areas of interpretations and thoughts which contributed to new insights regarding the experience of caregiving relationships in dementia care. Each interview was independently transcribed by myself and each reading progressed from initial thoughts and interpretations found in the data, to more detailed, structured coded annotations.

My own personal diary of thoughts and opinions was kept by myself as a means of bracketing and avoiding any critical engagement which could reveal any of my own pre conceptions of the experience. Smith (2011), explains how validity checks, such as member checks, can aid in supporting the credibility of the findings. This was achieved by cross checking the transcripts and interviews with both my project supervisors for peer validation. The continued process of referring back to the HCPs accounts allowed me to remain close to the verbatim data. All data analysis was conducted in English Language using the original speech of the participants, this includes utterances in the speech, colloquialisms, and pauses in order to maintain transparency in the conversational style.

Additionally, close attention was paid to the use of language by the participants, looking for a method of temporality in the data and the use of metaphorical language. This was the case for all five of the HCP's interviews. A list of emerging themes was then created based on the interpretations made on by myself (the researcher) for each individual transcript. The transcripts were then read again in order to ensure the list of themes was comprehensive and that all the extracts corresponded to the relevant themes. Finally, after completing this process for all transcripts, the transcripts were looked at again to check for recurrent themes between the participant's responses. As a result, a list of super-ordinate and sub-ordinate themes was created. The super-ordinate themes were developed under the auspices of having more than three participants having recurrent themes present. The super-ordinate themes were then discussed with my supervisors.

Ethical approval was granted from School Research Ethic and Integrity Committee, School of Human and Health Sciences, University of Huddersfield (See Appendix C). All participants were required to give fully informed consent. Permission was sought from the manager of the care provider via verbal permission to interview the staff members. All participants were given an information sheet drawn up by myself, followed by a consent form which they were required to sign which can be found in the appendix of this thesis. All participants had the right to withdraw at any given time before or after the research was conducted and they did not have to give a reason for their withdrawal. Participants were made aware of this in the information sheet and informed of the deadline of withdrawing data after the research was conducted (See Appendix D).

All the information collected was kept confidential and all recorded data from the interview was stored on a secured password protected hard drive at the University of Huddersfield. The consent forms were stored in safe locked file. Participants were aware that their place of work would not be disclosed at any point in the final write up. To protect the anonymity of the participants no real names were used in this research and the care providers name were not disclosed. Participants were aware and agreed they would be identifiable by occupation and all of them signed, as part of the consent process, agreement allowing their direct words to be quoted in the analysis.

The participants were made aware of where to get help if they felt they had been effected by some of the discussions in the interview, which was explained before the interview began. A debrief was also offered to the participants if they felt they needed it. In respects to researcher safety, a risk management form was completed. Examples of these protocols and be found in appendix E.

Maintaining confidentiality while carrying out qualitative research raised unquestionable doubts regarding the identifications of a person's known characteristics despite there being no direct identification of participant identity. Deductive disclosure can be described as internal confidentiality, which occurs when traits of individuals are made identifiable in research reports (Kaiser, 2009).

Researchers often face quandaries with attempts to convey detailed, accurate accounts of the social world and protecting the identities of the individuals who have taken part in their research (Kaiser, 2009). Some researchers would remove identities to create a clean data set. In this particular research, respondents actual names were replaced with pseudonyms. Additionally, in order to avoid possible identification, the quotations used in publication have been written in English Language and the participants have signed a quotation agreement, stating their consent to be quoted directly (See Appendix, A).

Pilot study

Larkin (2006) addresses one particular point that is important to consider, bearing in mind the context of this research project. He explains how within health psychology, many IPA studies have tended to be 'over-cautious', meaning the participants concerns are summarised, yet are not developed further to reach an interpretative or conceptual level. Larkin (2006) also describes many concerns with conducting an IPA project for the first time. He explains how IPA is attractive for its accessibility, flexibility and applicability. However, the subtlety and complexities of IPA's aims can be often overlooked and misconceptions are occasionally made leading to 'descriptive outcomes.'

To address these particular concerns, I conducted a pilot study in order to see how the participants would potentially respond to the interview questions. This was done to assess whether their answers were meaningful and to learn how to access those more meaningful responses, which would lead to a greater depth of interpretation. For the pilot study I selected

a family member who previously owned a residential home. I believed she would be able to answer some of the questions objectively. As she was a family member it removed the pressure of interviewing for the first time. The pilot study was audio recorded and listened back to evaluate the flow of the interview.

On reflection, the pilot study aided in further developments of the interview questions to access more meaningful responses and more engagement. Initially, many of my original questions in the pilot study were perhaps too long and there was often some confusion on behalf of the interviewee as to what I meant by the questions, this therefore interrupted the flow of the interview. I discussed these particular concerns with my supervisors and reassessed the questions. I then altered the questions using more opened ended ones which, in turn, resulted in more detailed responses in the final interviews.

This chapter will introduce the four superordinate themes that were identified through the application of IPA as described in Chapter 3. I will then present the findings in relation to each of the themes, supported by verbatim quotes from the interviews. The interview data has been categorised into four superordinate themes:

1. Trying to remain positive: 'glass half full in all situations.'
2. Experiencing variety: workdays, individuals and reactions.
3. Emotional intelligence: caregivers' experience suppressing their own emotions and maintaining the human relationship.
4. Growth aspirations: developing self as a caregiver through the experience of time.

An Overview of Themes

A brief outline of themes follows, succeeding in a more detailed discussion below. Initially, I categorised the raw data into four superordinate themes to reflect the experience of caregiving relationships in dementia care. The following table includes three columns. The first depicting the initial superordinate themes, the second demonstrating the sub-themes which routed as a result of the superordinate themes; and the third providing density of evidence for each theme (Smith, 2011).

Table 3 – Tables of themes

| <u>Superordinate</u> | <u>Subordinate Themes</u> | <u>Density of Evidence</u> |
|--|---|--|
| 1. Trying to remain positive: 'glass half full in all situations.' | <ul style="list-style-type: none"> • Making the most out of a negative situation and keeping a sense of humour. • Little things mean a lot. | Stacey (5 extracts) Masie (2 extracts) Tammy (3 extracts) Samuel (2 extracts) Catherine (2 extracts) |
| 2. Experiencing variety: workdays, individuals and reactions. | <ul style="list-style-type: none"> • Expect the unexpected. • Every day and person is different. • Reactions vary • Knowing how to respond. | Stacey (2 extracts) Tammy (1 extract) Catherine (3 extracts) |
| 3. Emotional intelligence: Caregivers experience suppressing their own emotions and trying to maintain the human relationship. | <ul style="list-style-type: none"> • Care-givers suppress own feelings. • Putting yourself in their shoes. • Emotional feelings towards job roles. • Communication • Friendships, empathy, and understanding | Tammy (3 extracts) Stacey (3 extracts) Catherine (2 extracts) Masie (1 extract) Samuel (1 extract) |

| | | |
|---|--|---|
| 4. Growth aspirations: developing self as a caregiver through the experience of time. | <ul style="list-style-type: none"> • Hopefulness for the future. • Professionalism. • Awareness of what hinders growth. • Relationship Growth. | Samuel (1 extract) Stacey (2 extracts) Catherine (4 extracts) Masie (2 extracts) |
|---|--|---|

Superordinate theme 1: trying to remain positive 'glass half full in all situations.'

The following analytical data sections explore the participant's process and perceptions regarding an active effort of trying to remain positive. The following sections elaborate on a mind-set of immediate positive thinking on behalf of the participants, regardless of the challenges they may face. All five participants expressed immediate positivity towards their job roles, and a sense of pride in themselves when they reflected on the work they do. All participants showed a wholehearted attitude towards their relationships with residents and spoke about them in a positive light. Most participants expressed how it was important and mind settling for them to understand that negative situations can be turned into positive ones. They often expressed a sense of having no choice but to be positive in all situations, almost as if it was a requirement of the job role. Which brings me to the first subordinate theme of this master theme:

Subordinate theme: how it was important and mind settling for participants to understand that negative situations can be overcome by keeping a positive mind-set and sense of humour.

It appears this is a core element of the participants' experience of being a caregiver in a dementia care environment. This is due to a personal understanding of the potentially negative reality of living, and caring for someone with dementia. Caregivers place some form of value on turning negatives into positives by maintaining a sense of humour. Therefore, consider this mind-set as a part of their job role.

Masie experiences the process of continuously trying to remain positive. She appears to believe that looking at things negatively will impact on the relationships with the residents, and hinder the chances of progress;

"erm, I don't really look at negative, I try not to, I try and look at everything as positive, you know if you're looking at negative, then things aren't ever going to get better for that person, to improve with them, you know if there new here, and we don't seem to be getting far with them, just keep trying and trying and eventually you do, cos it can be hard and it can take them a while to settle in sometimes, and the surroundings, other people that live here, it's, they got to get used to them as well, but hmmm.." (Masie, transcript 3, p. 155, line 77.)

"Good. I think so anyway, I enjoy my job, you know, some people come and it is just a job to them, well I don't look at it like that?" (Masie, transcript 3, p. 157, line 146.)

Masie understands how it is perhaps occasionally quite hard to remain positive in her job role. Masie says, "I try not to" which could indicate that there is a conscious effort to try and remain in this mind-set towards caring. She talks about a process of constantly 'trying', almost as if it is repetitive process, concerned with helping the residents to settle using this sense of positivity or particular mind-set. Masie uses utterances such as 'hmm' and 'erm' perhaps indicating that there might be some further thoughts which could have perhaps been explored further by the researcher. Masie explains how it can be hard for residents to settle in sometimes. This could be referring to the some of the struggles that come with living with dementia. This perhaps highlights how an environment can play a role in the resident's life. In this instance, Masie could be suggesting that environmental changes are linked to dementia, therefore, as a caregiver it is their job to help that individual feel comfortable in a new environment.

Masie also expresses an overall positivity towards her job as a whole, she explains how she “enjoys her job”, suggesting that she has a positive attitude towards the job and she gets more from this job than the typical practicality of having a job. On reflection, it would be interesting to try and comprehend what sort of emotional impact the act of ‘constantly trying’ and forcing herself, and others, into this mind-set has on an individual. Especially considering the repetitiveness of putting oneself in this position on a daily basis.

Furthermore, Tammy describes the type of personality she likes to portray and contribute to the relationship with the residents living with dementia;

“Myself erm, positive! I think I am quite a positive person” (Tammy, transcript 5, p.175, line 88).

“I like to be like the positive person, I like to make them smile, like crack a joke, cheer them up because it’s not like the happiest environment for people to be in, so the best thing you can do is try and make, make it more positive” (Tammy, transcript 5, p. 174, line 60).

“I talk, I ask them a lot of questions about their life and I ask them like, I ask them what they used to do, I find out a bit about them, so then we can find like mutual things in common then can’t we, and then we can engage in a conversation about that” (Tammy, transcript 5, p. 176, line 102).

Once more, the idea of immediately thinking positive can be perceived here, ultimately trying to position herself into this positive personality that is the ‘caregiver’. Tammy presents her self-perceptions to the researcher in a way that guides a belief concerning how particular personality traits aid as a good facilitator for good relationships with the residents.

Tammy describes the experience of initiating conversations with residents by getting to know the residents individually, ultimately, forming the basis for a positive relationship. Tammy also expresses curiosity about the residents she works. This could give the impression she is genuinely interested in learning about the residents. This may indicate the nature of naturally building relationships like you would with anyone else. This can be linked to the knowledge of

personhood, which is discussed in the literature review, demonstrating the attempts to keep the relationship human.

This formally leads to one of my sub-themes. The idea that a 'sense of humour' contributes towards many factors related to the experience of caregiving relationships. Tammy talks about how she likes to crack a joke and relishes in making the residents smile. Tammy is acquainted with the underlying negative connotations of working on a residential dementia unit, therefore, feels it important to make the experience more positive for the residents. It gives the impression that her experience of being a positive person is not only beneficial for the relationships with the residents but for herself too. This is because she explains how she enjoys being this type of person. Tammy also explains how her approach to maintaining relationships on the dementia unit; she does this by getting to know the person. It could be that Tammy believes that asking questions is a way of finding a common ground with residents. For instance, asking about their life and backgrounds and by using jokes to cheer them up.

Stacey was asked about her experiences of working with residents with dementia, both positive and negative. Stacey responded with;

"I think to work with people with dementia you have to like people with dementia, I like the demographic because I prefer old people, I've always enjoyed working with old people, that was my thing so to speak, I find them amusing, I find them kind, I think you need a lot of patience if you haven't got any patience don't bother coming because they can test you" (Stacey, transcript 4, p.163, line 36).

Stacey explained prior to this question how long she had worked with residents with dementia residents for over twenty-four years. She has a great deal of experience, skill, and knowledge when working with dementia residents.

Considering her experience, she comments on how care-givers have to omit a natural liking towards people with dementia and older individuals. She also points out how she finds the older generation amusing. Therefore, you can see how a sense of humour is important to her, especially considering the nature of the job. She has high opinions of older people and sees

the best in the individual, which again, links to the idea of immediate positivity. Stacey expresses language such as “don’t bother coming” which could be interpreted as quite a strong and bold phrase, perhaps highlighting her emotion and confidence towards what she believes is important, in this case, patience being an admired quality.

Stacey correspondingly comments on how she sees the positive in every day and uses the synonym of her “glass always being half full;”

“Yeah I understand what you mean, I’m trying to think really, I think, there are lots of positives every day, I’m the type of person, my glass is always half full always, I normally look for positive anyway, Erm I can probably turn a negative into a positive, I’m probably not the best person to ask, I’m trying to think of a negative situation really, I was strangled by somebody once” (Stacey, transcript 4, p. 166, line 97).

From this comment stemmed the idea for the overall theme of this section of data. I believed it summed up and related well to the experience of all the participants. Stacey seems to portray an overall positive outlook on every working day, but it also gives you an insight into her personal attitude towards life and how she views herself personally. The use of this phrase could imply that Stacey is positioning herself to the researcher as quite an optimistic and positive individual who actively seeks these qualities in her colleagues when it comes to recruiting. Stacey uses the phrase “glass is always half full.” This could perhaps mean that her thought process always leans towards finding hope and optimism in her experience of situations.

It is interesting how she explains the experience of being strangled by a resident. Stacey appears not to view this as a serious incident, this might imply that she has a high level of experience and familiarity with handling these types of situations. However, it could also demonstrate how dealing with behaviours like this are perhaps normalised in a dementia care environment. Stacey elaborates on the experience of being strangled below;

“yeah erm and it was down really, we was in a confined space, and he wasn’t, he wasn’t erm sure of what’s going on, and he got really panicky, and he went to attack me, and we went, and it set of quite negative, because he has his hand properly around my throat, and there were two girls who were, they said I’m going to, I’m trying to break his hand away from throat, and I’m karate chopping him, which you have, you know trying to make him, and I was trying to get a grip of his fingers, and I couldn’t because

he's quite a big strong man, and the two girls were actually pulling on his arms to pull him away, and it was in here and he was cornered and erm, but he eventually, and it was a bit, it shocked me more than anything, I wasn't hurt, I was shocked, and that was negative, and we all just sat, and it was a strange situation really, because he just stopped, I was just sorta, regaining my composure, and the two girls that were pulling his hands off, collapsed laughing, and I, as I came round, and he was just stood there confused by the whole situation, and I was just like why you laughing, I said to —'you face it was so funny', so then I started laughing, and then the man started laughing, can ya see, and I mean it could have been serious, because he had a proper grip of me throat, and that was quite negative. But if the girls hadn't of started laughing, I could have been umm, you know escalated to this big serious situation" (Stacey, transcript 4, p. 166, line 104).

Stacey's narrative of this experience is very interesting in the way she expresses herself whilst telling this story. On attempting to understand Stacey's experience of being strangled, to me, I noticed that Stacey and other colleagues are perhaps using humour, laughter, and jokes as a means of coping with potentially stressful situations in the workplace.

Potentially seriously situations can be turned around in the way in which you handle them and Stacey believes this to be an important dynamic in her experience of being a caregiver on a dementia unit. It appears that using laughter and humour in these particular environments acts almost like a calming aid for not only the caregivers but the residents also.

Similarly, Stacey speaks about how as an employer she looks for a sense of humour and values personality characteristics more than qualifications themselves;

*"Yeah, one thing that is absolutely vital over any o level or a level or degree is a sense of humour, if you don't have a sense of humour then don't apply, and a sensitive nature, because you can't take anything personal *laughs*" (Stacey, transcript 4, p. 168, line 151).*

Stacey mentions how you must not take anything personal. This maybe means to not take offence to certain aspects of the job, also maybe meaning that to be a caregiver in a dementia unit you have to have 'thick skin'. As a result, it gives an impression that Stacey has a specific set of beliefs, attributes, and values which she believes correlates to the true way to be a caregiver. As Stacey appears to be a knowledgeable member of staff, she places personal value on the process of actively looking to instil this particular mind-set upon recruited staff

and new staff members. This could perhaps be related to the emotional demands which come with caring for individuals with dementia.

Subordinate Theme: Little things mean a lot

A further sum-theme contrary to this superordinate theme is the notion of 'little things mean a lot'. This appeared salient when talking to the participants about their experience of caring relationships. Most participants explained how the reality of dementia is actually quite unsettling to them, therefore, small acts of kindness or small positive experiences hold a lot of meaning to the caregivers. Samuel spoke about the experiences which he found most satisfying during his time as a caregiver. He responded;

"It's all just little daft stuff like unfortunately, some have passed away now, but times when like, you just have half an hour sitting watching boxing with a guy, like I couldn't care less about boxing or football really, but just sitting having half an hour watching it with the residents, there the little bit's that I remember" (Samuel, transcript 1, p. 131, line 104).

"There's been that many residents now, I'm struggling to remember them all in my head, but it's the little moments you remember the most" (Samuel, transcript 1, p. 131, line 110).

Samuel gives the impression that little moments with the residents are the ones which are considered the most meaningful to him. Something as simple as watching television with a resident, Samuel finds these moments satisfying. He highlights how the fact he is watching boxing does not matter to him. I think what he might be trying to imply here is that the opportunities to sit and interact with the residents are the most memorable.

Similarly, this perhaps indicates how the experience of time can play a role in the experience of caregiving relationships, and spending time with the residents allows the opportunity for relationship growth and bonding. Furthermore, I can perceive how the relationships with the dementia residents are similar to those which you would develop with say a friend or a family member, as these are the sorts of activities you would perhaps do with someone close to you.

Ultimately, this perhaps demonstrates how caregivers try to act in the way in which a friend or a family member would and build a relationship with them like you would with anyone else.

Furthermore, Catherine highlights how carrying out small acts and knowing what each individual likes aids in the process of bonding with the residents. She expresses knowledge of this particular individual's likes and dislikes and explains how it makes her feel;

"Erm so there's one resident who erm loves having a shave in the morning, and if he doesn't have a shave, he gets quite annoyed by it, so when he does he's really grateful, I think that's, they won't remember you in an hours' time, but when they're really grateful, it makes you feel good, make you feel like you're doing, makes you feel like you got a better bond with them" (Catherine, transcript 2, p. 144, line 102).

"ooo yeah, erm, there's little things that you do, erm, you could, erm there a resident who doesn't really like getting up, and erm, too, when she hasn't got ready in the morning, she's in a very bad mood, and once you encourage her and eventually persuade to have a wash or a shower or put on a bit of makeup as she does, she is a ten times better mood, and she's so grateful and thankful, erm and she like can't believe how much better I feel now. It's like that's satisfying because you feel like you persuaded her to do it and she will have a better day now for it" (Catherine, transcript 2, p.147, line 166).

Again, Catherine is talking about the little things that she can do as a caregiver that really make a difference to the individual's day and mood. She expresses joy when the residents show her gratitude towards her. It, therefore, could appear that the idea of remaining positive and encouraging towards the residents, by paying attention to the detail of small acts, benefit's everyone involved in the experience. This could correlate with the theme of remaining positive and opting for an optimistic persona and energy towards the residents appears to create a settled atmosphere for the day ahead.

Additionally, it may also demonstrate how having and trying to create this positive, optimistic aura about yourself as a caregiver can deflect onto the residents and create stronger relationships which provides quality care for the residents. She also experiences having to use persuasion and encouragement in order to convince residents of carrying out day to day tasks which, perhaps, we ourselves would automatically do without needing to be persuaded.

To me his perhaps highlights the physical impact dementia has on an individual, leaving that particular individual with no motivation to do the usual daily tasks we would normally do.

Similarly, when Stacey was asked about her experience of what brought her job satisfaction Stacey replied with;

*“Err, I think they’re so small, that probably, when *blank* drinks a full drink, *laughs* so little things more than anything, because you can’t expect big things in a job like this, when somebody who hasn’t eaten for so long, well eats when things improve, it not, looking after people with dementia not a lot of things improve, do they, in fact, they go the other way, don’t they, and it’s when, erm it’s the little things with dementia, when they suddenly say something and they haven’t spoken for weeks, it takes you by surprise when something takes you by surprise like that” (Stacey, transcript 4, p.167, line 124).*

Stacey also highlights how little things mean a lot to her in this extract, I think what Stacey might be referring to here is the gradual progression of dementia that, unfortunately, residents go through. This could mean that fulfilling residents basic needs mean a lot to the HCPs. This is perhaps due to the nature of dementia, as basic needs become more difficult to fulfil due to certain factors such as behaviour challenges, cognitive decline, and deterioration of mobility, etc. Stacey explains how you cannot expect big things in the job role and I think again this is referring to the reality of dementia, therefore focusing on the fulfilling the needs of the residents and the small acts allow the staff to find meaning in their job roles and making the most of the situation. Additionally, this extract illustrates how the staff has feelings of gratitude towards the small positive instances which make an impact on the care-givers, and this is done by removing unrealistic expectations, therefore making the person appreciate the small things more.

Superordinate Theme 2: Experiencing variety. Workdays, individuals, and reactions

This particular theme developed from participants speaking about their experience of variety with not only the working day but the difference in individuals and reactions of their residents. Most of the participants spoke about how every day was different and how each resident has

their own individual's needs and ways of responding. All participants demonstrated a knowledge of understanding towards the philosophy of 'expecting the unexpected'. From this I developed my sub-themes which corresponding with the overall superordinate theme.

Subordinate Theme: Expecting the unexpected. Because every day, individual, and reaction is different

Stacey was asked to speak about how it made her feel when dealing with particular challenges. She responded with;

"every day is different, it doesn't mean that you're going to have the same day tomorrow, I think that's what makes you come back, because you can have a day like that, but the day after will be absolutely something else, you know, it makes you laugh more than it makes you cry I always say" (Stacey, transcript 4, p. 163, line 47).

It could appear that being able to experience every day differently is perhaps a positive factor contributing to staff morale. Stacey explains how this is what she thinks makes her come back to work the next day. It could also mean that some days may be quite difficult to deal with, additionally suggesting that caregivers may have to move on from difficult situations quickly in order to keep up with the unpredictability of the job. It may be feasible to suggest that HCPs enjoy the variety and unpredictability of the job, as Stacey explains how it makes her laugh more than it makes her cry. Therefore, it could mean that the enjoyable moments outweigh the difficult ones. Similarly, Tammy also explains her experience of the working day;

"every single day can be different it depends what moods people are in, some people can be in a happy mood so the environment can be happy and people could be miserable, it all depends every single day is completely different" (Tammy, transcript 5, p. 172, line 3).

Tammy talks about how no two days are the same, and explains this as being a result of what moods the residents may be in on that particular day. Tammy experiences a happy environment when people are in a happy mood. Tammy uses the phrase "miserable" to describe how the environment can be in the home on occasion. She also says "it depends what mood people are in". It appears that Tammy is not necessarily referring to anyone in

particular, which could mean that the mood of the environment can be influenced by a variety of people. Ultimately, it is interesting to see how an individual's mood can affect the atmosphere of the home, which demonstrates the high levels of emotion attached to the job and also demonstrating how connected everyone is to one another.

Tammy used the phrase "miserable" which could rise as quite a strong choice of description. This perhaps relates to the reality of living with dementia. Retrospectively, the reality of dementia can potentially be quite 'miserable' considering the fact there is no cure for dementia as of yet, it can be quite distressing for families and the individual especially in end of life cases of dementia and a care-giver witnesses all these events and the progression of the condition on a daily basis. Tammy could be referring to these events when she explains that the environment is miserable sometimes.

Furthermore, Catherine speaks about her experience of starting working on the dementia unit and her understanding of what the reality of when she began as a new starter on the unit;

"erm , on starting any new job, is quite daunting, but I think it is especially scary job to come into, cos there's coming into a job and not knowing what to expect, but this is job where you don't know what to expect every day, it can change every day, you can have a really good shift and a really bad shift, cos you can't predict behaviour, so there's constant challenges with that, erm I think over time you get used to certain personality traits, erm you understand them more, you understand them as an individual, so over time there isn't that much that shocks you, most situations you have been in before, so you feel like you can handle it, obviously you get the odd one where don't and it's completely new, but I think a lot of the time, over the years of being there, you just kind of get used to it" (Catherine, transcript 2, p. 148, line 202).

Catherine explains how she feels when starting a new job, but adds how you have the added fear of coming into a job role which is unpredictable on a daily basis. This could be potentially quite stressful and emotionally taxing. She has experienced variety in work days being either good or bad and she puts this down to the unpredictability of behaviour. This perhaps demonstrates the complexity of dementia and how it can affect that particular individual, which means care-givers need to have the ability to acclimatise to fluctuating levels of behaviours and moods and handling them appropriately. She expresses how over time you begin to understand different personality traits, which could correlate to understanding the individual

on a personal level. Catherine is perhaps implying that a level of emotional control is perhaps required on behalf of the caregiver. Despite having their own personal feelings towards the job role and the stress they may be under adapting to these circumstances, they also have to handle and manage resident's emotions.

Catherine holds some value towards getting to know the residents on a personal level, and explains how this aids in understanding what might trigger a reaction to a particular act. This perhaps demonstrates the variety in individuals and the level of personalisation required to carry out the care needed;

"I think there's a great importance on, getting to know person as an individual, because each individual has certain things that can trigger the bad side, and ways to calm them down, one technique doesn't necessary work for every single resident, you have to get used to that" (Catherine, transcript 2, p. 149, line 214).

"Erm my understanding of dementia, erm I think I understand that it varies in each person with dementia, it doesn't affect the other person the same at all. Erm, it can affect people very negatively, it can bring out, it can change the personality completely, could have been a nice, happy, easy going person, it can change them in like an aggressive person, no fault of their own, it's just what it's done to them. Erm it... it's a hard question" (Catherine, transcript 2, p. 142, line 55).

Stacey was asked about her perception and experience of person-centred care principles.

She reflects on the personalisation required to care for someone living with dementia;

"There's no other way really, you got to treat that, especially with dementia, I'm not sure about other conditions, but there is no other way with dementia, there is no cover all with dementia because every single one of them is different, so you have to deliver person-centred care, and that's where getting to know them comes in, once you know them, and you know what makes them tick, and you know what upsets them, then you can look after them" (Stacey, transcript 4, p. 168, line 156).

Stacey agrees with the idea of getting to know the individual on a personal level which therefore reflects the principals involved with person-centred care, she explains that this is the only way of caring for someone. Stacey uses language such as "there's no other way" and "you have got to" which suggests to myself that Stacey has quite strong feelings and beliefs regarding the best way to care for someone living with dementia. She highlights the idea of

keeping the human relationship by the way she explains the procedure of getting to know the residents like you would with anybody else.

Superordinate Theme 3: Emotional intelligence. Caregivers suppress own feelings and attempt to keep the human relationship

As a result of the previously discussed extracts above, this therefore brings me to my third superordinate theme; the idea of getting to know the individual requires a level of emotional intelligence and understanding of individual's needs. Emotional intelligence can be explained in respects to how an individual contributes to the world with an effective self-management. It is a comprehension of how much sensitivity one person has towards one's own or others opinions and emotions (Senyuva et al. 2014).

Most participants spoke about how they handled emotions and situations on a daily basis. My own personal interpretation of this theme revolved around the impression that emotional intelligence and compassion play an effective role in a dementia care environment. All participants appeared to have an underlying knowledge of knowing not to get 'attached' to residents considering the nature of the job role. However, most participants expressed how the reality of this concept is somewhat different, ultimately demonstrating the nature of being human and feeling somewhat connected to the residents they care for. To me, it appears that there is a conscious effort on behalf of participants' to feel obliged to suppress their own emotions of grief and distress, as part of an appreciation and understanding towards the reality of the job role.

In this extract, Catherine is speaking about how you can find yourself becoming quite attached to residents as you witness and almost become a part of their journey in the care home;

"I think, if you get quite close to a resident, or ones been there for a long time, you have kind of seen them from, the start of their dementia to the end and you have seen them progress, and then I think when you lose that person, I think it can affect you, you try and not let it, but when you have known them a long time it obviously does, it's something you think about when you come home from your shift" (Catherine, transcript 2, p. 144, line 102).

Catherine is explaining how residents can come into the home and live at the home for a long time and it is because of this that you find yourself forming a bond with them. From this I can infer how care-givers are perhaps becoming a vital part of that person's life and demonstrates the attempts to keep the human relationship like you would perhaps have with a family member, etc. Additionally, Catherine speaks about experiencing a sense of loss when a resident passes away, indicating a level of emotional connection between herself and the residents, due to the reality of the job role she is aware that she has to try suppress these feelings but despite the efforts to suppress how she feels she finds herself taking these feeling home with her.

She also speaks about how she believes the residents interpret the relationship with herself. She explains how she been in situations where her age is a contributing factor affecting the type of relationships she has with the residents;

"I've had it where I've been treated as grandchild, so I think, I think the relationship can get a bit blurry to them, they don't really know who you are, I think it's nice to be a familiar face, you know, a reassuring face. I think that's the best thing that they can get out of it, it would be nice if they recognised you, even if they didn't really know who you were, they kind of thought, I know that there a nice person, I remember them, I don't know what I remember them from, but I recognise them from that they was nice to me, I think that's best" (Catherine, transcript 2, p. 147, line 179).

Furthermore, Catherine explains the complexity of dementia in the later stages when she refers to the relationship becoming quite "blurry" to the residents. She also expresses an acceptance towards how the residents wish to view the relationship they have with her, which in turn, perhaps shows her understanding for the resident's dementia and also demonstrating the compassionate nature of human relationships. Catherine is allowing whatever relationship that residents wants to have with Catherine unfold to comfort that person, as perhaps being seen as a grandchild to a resident with dementia could bring some comfort to that person, especially considering their position. Additionally, she highlights how by being that "familiar face" regardless of whether they remember you or not you. Catherine internally knows she has been kind and hopes they feel the same back in that particular moment, ultimately

expressing a sense of satisfaction and comfort in the fact she was able to be a familiar face to someone living with dementia.

The following extracts are taken from Tammy's interview. She is talking about how the relationships with the residents develop over time. She speaks openly in regard to her own emotions, demonstrating how there is some element of human relationships and bonds between herself and the residents, explaining how one another moods and deflect upon each other whether it be a happy mood or a sad mood;

"Yeah you got to be open minded about everything, some things can be emotional and make you sad, like certain things can happen, that can be emotional, and sometimes like you become their friend, so like, when they feel sad you feel a bit sad and erm when your happy, they become happy, you do what you can to try and make the positive about like the negative that's going on" (Tammy, transcript 5, p. 173, line 36).

"I know personally, you shouldn't take anything home with you, but were only human our self aren't we, I find it emotionally distressing sometimes, the things that go on, so sometimes I go home and think about what's happened in my day, but I know that personally I can't dwell on it, because I know that it's not affecting my life is it?" (Tammy, transcript 5, p. 175, line 44).

"The ideal relationship is to get to know them, get to know what they like, get to, to, we have the time to get to know them personally, we have that advantage, don't we, we get to know them personally, because we get more time with them, so we get to know what they like, what they don't like, what, if there in a bad mood, we can just look at them, and know they are in a bad mood" (Tammy, transcript 5, p. 175, line 80).

Tammy elaborates on the experience of friendship developing between her and the residents with acceptance towards the knowledge and understanding the reality of not letting things affect you despite having that initial connect. It appears to myself that her approach towards understanding her own emotions is to reflect upon them and accept that ultimately the circumstances which she may have found particularly distressing are not directly linked to her own personal life outside of the working environment. This might indicate the level of emotional intelligence and emotional self-management required on behalf of the HCPs.

In this particular extract Samuel understands the relationship with the residents as being somewhat of a friendship;

"It's trying to break down the idea of you being the carer and them being the residents, you're just two adults, or however many adults, working together. Yeah yeah. Have a friendship with them as much as anything" (Samuel, transcript 1, p. 132, line 137).

Samuel uses language such as *"trying to break down the idea"* which is interesting. Perhaps indicating some internal thoughts or opinions here. The concept of "break down" highlights to myself that he might believe there is some unspoken notion of thought to be challenged here. It appears Samuel has an understanding that caregiving is not necessarily about providing the practical care needed, but also making a conscious effort to connect with residents on a level of more than basic care giving itself. He speaks of having a friendship with the residents which demonstrates how Samuel values and sees the relationship he has with the residents. He uses the phrase *"working together"* which demonstrates an attitude of treating people as equal and encourages the independence of the residents.

Similarly, in these particular extracts, Stacey speaks about her opinions regarding how she feels is the best way to care for someone living with dementia. She highlights the importance of developing and maintaining relationships when it comes to effectively caring for someone living with dementia. Additionally, she pays particular attention to the idea of developing a human relationship as you would with anyone else, which demonstrates a person-centred attitude towards practice;

"In my opinion, the best way to look after someone with dementia is to have a good relationship with them and to know them, and it enables you to look after them, you get to know how they feel, in a way you can sometime second guess them, you guess what them, and it enable living with dementia. She you have looked after them and you know how they tick, and you can also prevent situations, by knowing if you do one particular action, it will lead to this particular action" (Stacey, transcript 4, p. 164, line 61).

Uniquely, it is interesting to note Stacey's conceptualisation of 'personal knowledge' aiding in predicting behaviour, actions and preventing situations. Above all, having its own practical benefit's in practice;

"Erm, it's sometimes about judging people moods, if you see that someone you know is in a certain kind of mood if you try to perform an intervention, like going toilet, while they're in that particular mood, there are going to be consequences, so it's always best

*to stand back and wait till that mood changes, and that's probably true of quite a few people. You are not going to get anywhere so don't bother *laughs*, don't work them up and don't work yourself up"* (Stacey, transcript 4, p. 164, line 69).

"Yeah it just like everyday life, your relationships with people who haven't got dementia are all different, so they wouldn't really be any different, they're still people, they all got their own personalities, dementia or not" (Stacey, transcript 4, p. 165, line 76).

In this particular extract, Masie talks about how she loves working with the residents living with dementia. She shows positivity and emotion towards the job role by using adjectives such as love and amazing, which indicates some personal meaning to the role itself and also the residents she works with;

"I love working with them, I think it's amazing. it's good to know a lot about dementia I think, a lot of people don't understand it, you don't know what's going on, in each, in and everyone is a different individual there all, none of them are the same, erm I'd love to know what they think, I would love to know that, you from what they say, what they're actually thinking in their mind, erm, you know one lady we have got, she will talk about something, but she will be doing something with her hands like she was a machinist or something, and she was nothing of the sort, you know and when she's talking, she's happy, and gets carried away with her talking but you haven't got a clue what she's talking about. You just have to agree with her and she agrees back with you, and it's pretty sad that we can't understand what she's wanting you to know and what she's telling us, but whatever it is in her mind, it makes her happy" (Masie, transcript 3, p. 154, line 56).

Masie demonstrates curiosity towards the individuals living with dementia as she explains how she aspires to understand what they are thinking and is sympathetic in the understanding that it is hard to understand and comprehend their needs sometimes due to the complexities that come with dementia itself. Masie also makes an interesting generalisation here in that she explains how "it's good to know a lot about dementia, a lot of people don't understand it." This perhaps demonstrates how complex dementia can be, as she believes a lot of people do not understand the disease. She highlights how she feels it is beneficial to have a good understanding of how dementia affects people, and is perhaps referring to past stigmas that came with having a diagnosis of dementia. Masie, however, does not refer to any specific people who do not understand, therefore, it would have been interesting to explore her

thoughts further to grasp an understanding why she believes people do not understand dementia.

Superordinate theme 4: growth aspirations, developing self and the future of caregivers through the experience of time

This final theme developed towards the end of the analytical process. After interviews were completed and transcribed, I soon began to notice patterns in the data. It seemed to myself that whilst speaking to each participant, they spoke about some kind of journey/process they have encountered prior to becoming a caregiver on the dementia unit. Each participant spoke about how they have developed their experience and skills over time and believed in being hopeful towards the future of caregiving relationships. From this stemmed the concept of all participants having growth aspirations not only for the development of themselves in caregiving but for the future of caregiving training, practice, and relationships in dementia. Successively, there were also growth aspirations involving the development of understanding and knowledge of dementia itself, which participants believed would improve caregiving relationships.

Incidentally, it appeared to me that the experience of time was a perceptible factor contributing to the overall experience of being involved in caregiving relationships. The concept of time was experienced by participants from a variety of angles. One is that time supports the development of skills, the ability to handle situations and allows caregivers to get to know the individual countenancing for a higher standard of care. Nonetheless, time was also experienced in a way that holds participants back in ways such as, not being able to provide as much one to one time, a limited amount of time to complete tasks, etc.

Similar to the idea of immediate positive thinking and the first superordinate theme discussed earlier, most participants also expressed positivity and optimism for the future. Most participants were hopeful that the future of caregiving relationships would ultimately improve

with time. Although this may be true, most expressed an awareness of the logical practicalities which could potentially slow down the progression.

As an illustration, in this particular extract, Catherine is speaking about her how she has progressed as a caregiver and speaks about how time can sometimes be a hindrance to the relationships in with the residents. She has experienced residents seeking attention, and explains how when the attention is not available some may use other forms of communication to get the attention they desire. She appears to have been in situations where this can sometimes have its consequences;

"I think that can cause issues cos you haven't got as much time, erm individual one to one time, I think some, when that attentions not there, they find other ways to get attention, you know they get bored sat there, they obviously want to do something, but that can cause problems, and bit much to handle, erm" (Catherine, transcript 2, p. 149, line 226).

"I definitely think the longer you have done it, the better you are with it like you'll see erm, people who have worked with it for quite a long time can handle situations a lot better, it doesn't seem to stress them out at all, whereas people, new members of staff who never crossed dementia before and they don't understand it as much, sometimes don't understand what they're doing, are not very calm when the handle things, and can panic" (Catherine, transcript 2, p. 142, line 73).

Catherine appears to be under the impression that the experience of handling situations comes with time and practice, she makes a comparison to new members of staff and explains how the unknown can make people panic. This might imply that over time you develop your skills and experience as a caregiver, and also develop an understanding dementia needs time. Additionally, it could be that she is explaining the growth each caregiver goes through throughout time, which may indicate that she has perhaps practiced handling situations. Therefore, the more practice she has the better she becomes. She also talks about not having enough one to one time which in turn leads to negative consequences. Perhaps highlighting how in order to be in the caregiving role, you must have the ability to manage time effectively and be flexible in how much time you spend with each resident. However, she makes an interesting point regarding how some residents may get bored. This could indicate a human desire for human connection on behalf of the residents, therefore it is the caregivers who have

to adapt and respond. Managing these emotions may be especially difficult in cases where physically or medically someone requires more attention than others. This could be due to medical conditions other than dementia.

Catherine later speaks about how she has been on the dementia unit for over four years and explains how overtime she has got used to the many situations which may come up in the process;

“erm, I don’t, I don’t think about it very much anymore, I think, when I, when I first, I’ve been doing it over four years now, and in the very beginning, I panicked some-times, cos especially if there’s only a couple of you on shift, I think it can be quite daunting if you haven’t been in the situation before, and you don’t know how to handle it, but I think as the years have gone on, erm I haven’t found anything that has surprised me recently, so a lot of the situations seem to be reoccurring or you have seen it before so you know how to handle it, and you know the person as well, you get to know them, so you kind of get to know what calms them down, what agitates them” (Catherine, transcript 2, p. 144, line 91).

Catherine again talks about this idea that time seems to help you understand situations more. She explains how situations often reoccur, therefore you know how to approach them. Additionally, this extract also relates to the previous themes, keeping the human relationship. This is due to the way she talks about the process of getting to know the individual. It appears that Catherine has an awareness of her own personal growth throughout the process of working on the dementia unit. This is displayed in the way she compares her reactions from when she first started to how she would approach a situation now.

With regard to the idea of growth aspirations, Catherine appears to position her opinions in an optimistic manner towards the improvement of relationships in care;

“I think they will improve relationships because I think, ten years ago, there wasn’t much information about dementia, it seems to come to light so much over the past few years, there are a lot more charities and awareness about it, I think people understand it a lot more, things like Alzheimer’s society and Dementia UK, they do a lot, they try to raise awareness of it, I think because of that because over years more understanding of it people will be more aware of it, people will feel more prepared going into the job, and improve relationships” (Catherine, transcript 2, p. 151, line 269).

I think what Catherine could be referring to here is the gradual improvement in the generation of new knowledge about dementia. She could also be referring to the improvement of

symptomatic knowledge about the disease and how it can affect an individual living with the condition. In recent years, charities such as Dementia UK and Alzheimer's society have done a great deal of work to improve the populations' general awareness of the disease through various campaigns and fundraisers etc. for example, memory walks, jog on dementia and the fix dementia care campaign. These types of campaigns have the ability to reach out to a wide range of people in the population. As a result of new knowledge, Catherine suggests this will improve HCPs readiness to enter the field. Catherine explains how the current development of knowledge and understanding towards dementia aids in improving relationships for dementia care. She also highlights how she feels that people will be more aware of what is required from the job role. Perhaps presuming there will be less anxiety when people initially start the job.

Similarly, Masie also speaks about how people's general understanding of dementia has improved of the years;

"I really don't know but, I'm hoping, cos there is a lot of, what they call on telly, like documentaries on dementia, it's seems to be becoming more popular now, so hopefully it will improve, and there will be a lot more out there for them, you know, things for them to do, and more staff, I don't think the staffing levels are fair at all for dementia, because some of them do take time, working in a place like this, you know there is only 12 residents, but even when there's just three staff on, I don't think it's enough, you need time with them, you know to make them happy, today we made time for them, cos I do think it is important" (Masie, transcript 3, p. 159, line 196).

However, Masie expresses a degree of uncertainty about the future of caregiving relationships. This appears when she says "I really don't know but, I'm hoping". It is possible to presume Masie is hopeful regardless of the setbacks caregivers face. This appears to reinstate the value of immediate positive thinking which flows throughout these extracts. Additionally, Masie expressed concern regarding the staffing levels for dementia. Moody and Persut (2006), have previously discussed how poor staffing levels make the practicalities of developing practice challenging, thus resulting in a negative impact on staff morale which in turn reduces people's motivations to improve and develop practice.

Alternatively, Stacey expresses her opinions regarding limitations to the growth of health care. She speaks economically in respects to a belief concerning the lack of money in health care, followed by an awareness of the ageing population. As a result, this presents more pressures on health care services and the staff to provide the care required;

“Because there is no money, basically there is no money, the population is becoming more aged, there’s going to be more pressure, so I don’t think there will be much improvement, but let’s hope they don’t get any worse” (Stacey, transcript 4, p. 169, line 185).

“Erm I think if the training improves, and I think if every dementia unit, I think, erm, if, if they attract the right staff, I don’t particularly go for educated girls, I go for girls with a nice personality and a sense of humour, and it can, and training and training, and I think were a unit who has a lot of involvement with families, encourage families to not to opt out of the care but to opt more in, you know, cos it has to be a job for all us, not just us. You know, encourage families, encourage them to get involved, I mean we have got good families at the minute, families I think they need more help at home, you know, they need more GP input, I think medication has a role, and all that, I think it improves life, you know. I’m not talking about you anti-psychotics, I’m talking about your citalopram’s, and your donepezil’s, you know and your memantines, erm and just managing the condition, and I think give families more support at home, you know where, there not up all night, up 24 hours a day, because the families are becoming exhausted, and to give them more help and many not as many would have to go into care” (Stacey, transcript 4, p. 169, line 190).

One particular area of this extract which stands out is way Stacey focuses on training and understanding on behalf of the staff. It appears that the improvement of training and attracting compassionate staff perhaps means a lot to Stacey, as throughout the interview she explains how personality type is a vital factor contributing to the effectiveness of care. She speaks about “managing the condition” and explains how it is a job for all of us. This is particularly interesting as it demonstrates how exhausting it can be caring for someone living with dementia. This is effects of all people involved in that individual’s life. It appears that she believes the improvements lie within the way we respond to dementia, and tackling the symptoms as a means of managing the medical aspects the condition. Therefore, improving the quality of life for everyone involved.

Stacey also makes reference to the role of medication in dementia care, highlighting how she believes they can improve lives. Particular drugs she’s makes reference to, the Cholinesterase inhibitors (donepezil), were one of the first drug treatments approved for Alzheimer’s and

related dementias. They represented the first major therapeutic advance for dementia. However, debates occurred over their clinical and cost-effectiveness between the premarketing stage and the recent arrival of generic formulations signalling the final stage of their product life cycle. There is a general consensus that these drugs offer modest efficacy. (Gill et al. 2013). Stacey, however, says she had experienced their effectiveness in practice first-hand, and feels that this type of medication can aid in the overall management of the dementia in care homes.

Samuel continues to speak about his perceptions and experiences regarding PCC. This can be linked to the theme of growth aspirations. This is because Samuel appears to have experienced how time plays a role in dementia care. Additionally, he understands how time hinders the practicalities of delivering PCC;

"I think it's a great idea, but a lot of it doesn't always happen, there only ever so much time in a shift and only certain amount of time to do certain tasks, like you can't not get everybody up, you can't not feed everybody, those things have to be done, then, unfortunately, person centred care sometimes falls by the waist side, it shouldn't do, we don't want it to, but when you have only got so much time in a day, you got other decisions to what you can do and what you can't, like you can still use person centred care within the things you have to do, like we used to have a guy who always used to like wearing a suit and a tie every day, so we let him. But erm, you know, you got people who always know what they want to eat or drink, so you do use some person-centred care in that sense, you don't just say here are x amounts of the same meal, here have one each, but then things like, again, I mean, one on one time, that a lot of the time doesn't happen, wherein that sense the idea of person centred care gets lost" (Samuel, transcript 1, p. 137, line 245).

Samuel expresses positivity towards the principles of using person-centred care. He does this by using language such as "great idea". However, he explains how has tried to practice PCC in smaller situations, whenever this is possible. Samuel uses language such as "gets lost" which is interesting as it could perhaps link to a previous theme relating to the idea of how time is perceived by caregivers. What could be happening here is that Samuel perhaps feels that he is regulated by the practical time constraints of a running shift. Yet he appears to strongly value the principles of PCC. However, circumstances be that on occasion these principles are 'lost'. Additionally, this appears not to be a fault of anyone but perhaps a

message directed towards acknowledging how practicalities and logic, in essence, tend to come before person-centred care. He points out how you have to see to everyone. Therefore no matter how hard you practice the principles of PCC, inevitably, there are going to be instances when the decisions you may have to make, perhaps compromise the ethos of person-centred care.

Masie expresses hopefulness towards the future of caregiving relationships. Explaining how she currently does not believe they are “that bad”. Though she does express curiosity into reasons why they might not be as developed as she perhaps aspires to;

“Hopefully, I’m hoping it has improved, major, I don’t think it’s that bad, I don’t think it’s that bad on this unit at all, and maybe it is because they are younger?” (Masie, transcript 3, p. 160, line 209).

She uses the term ‘major’ to explain her expectations of improvement. Masie appears to think that relationships have already improved. This might be because she uses past tense, such as, ‘has improved’. Furthermore, her choice of word such as ‘major’, could indicate urgency in the need for improvements to be made. But this could also suggest there is quite a difference in what relationships used to be like. Although, it could be that Masie is experiencing some doubt in regard to future improvements.

In this chapter, I will discuss to what extent this research project has achieved its initial research aims:

- ✓ To gain a rich understanding of Health Care Professionals perceptions of client and caregiver relationships in residential dementia care.
- ✓ To understand how Health Care Professionals lived experience of working in dementia care environments impacts on professional caring relationships between the resident and caregiver.

Each participant offered rich accounts of their perceptions of client and caregiver relationships in their experience of working in residential dementia care and offered their personal insight into the lived experience of this phenomena. Their accounts deepen our understanding of how working in a dementia care environment ultimately impacts on the relationship between resident and caregiver. This can be demonstrated in the themes generated from this study and previous literature which relates to the field. This chapter will consider the findings in relation to previous literature in the field. It will introduce future implication for further research and practice and policy. It will then reflect on the research as a whole, paying attention to the choice of methodology and a summary of the findings.

How do these findings link to previous research?

Throughout the process of this IPA project, recurrent themes have emerged, illustrating the participants lived experience of dementia care, some of which can be linked to existing literature. Dewar (2010), highlights how there is an emphasis on strengthening the climate for care and promoting models of practice which centre on relationships. She talks about a model of compassionate RCC and explains this based on the practice of appreciative caring conversations. This is because she believes relational knowledge is important in delivering high-quality care particularly in settings for older people.

The appreciative caring conversations are made up of seven essential attributes which were; being curious; being courageous; collaborating; considering other perspectives; compromising and celebrating (Dewar, 2013). All participants exhibited many elements of these attributes. For instance; Tammy explained how she liked to get to know the person by being chatty and asking the residents questions. Masie also expresses curiosity when wishing to understand what the resident was thinking.

Additionally, Masie also explained how she thought it was essential to know a lot about dementia. Therefore, the theme of emotional intelligence can be linked to the previous work of Dewar (2010). This is evident when the participants express an understanding of how each resident can react to a particular scenario. By having this understanding of the person, it demonstrates how HCPs are using the seven essential attributes of appreciative caring conversations in practice (Dewar, 2010). The participants appear to carefully consider other perspectives and adjust their actions to suit that particular resident. For example, Stacey explains how it is important to judge a resident's mood and then make a decision on what action to take as a result of that mood. This therefore highlights the importance of personal knowledge in dementia care practice, as it can prevent negative consequences in practice.

It is perhaps useful to acknowledge how participants experienced the concept of PCC in practice. Most participants understood there were limitations to the growth of person-centred practice due to reasons explained in chapter four, such as caregivers not having enough time with residents. Also, lack of communication and training were considered to be further barriers hindering the delivery of PCC and the HCPs personal motivation to improve client-caregiver relationships. This is important to consider as maintaining relationships is what this research is focusing on. It would also be interesting to consider how one would apply Dewar's model to end of life settings, especially in cases whereby the physicality of having these 'caring conversations' might not be as easy.

Brummel-Smith et al. (2016) also discusses barriers to PCC. They explain how the physical workload can affect the effective delivery of PCC. They also highlight the importance of a well-

coordinated inter-professional team. This can aid in distributing the significant workload involved in arranging the care for chronically ill older adults. They understand how decision making may bring up ethical and medico-legal concerns which sometimes challenge the delivery of PCC, especially when considering risk and safety. For example, Masie argues that staffing levels for dementia are currently unfair. She believes that residents with dementia require a great deal of time in order to make them happy and this cannot be achieved with limited staff numbers. This in turn can put pressure on the staff's ability to deliver PCC and distribute workload effectively. Similarly, Stacey also stimulates some questions concerning the importance of personal knowledge of the individual in order to maintain safety and reduce risk. This therefore highlights the importance of Brummel-Smith et al. (2016) discussions concerning barriers to PCC and the effects of decision making in practice, as these are issues which are still experienced by HCPs in current day to day dementia practice.

Many participants expressed how time held them back in ways of not being able to provide them with the undivided care they would wish to offer. This is similar to the current study in that, the participants have to manage their time accordingly in order to accommodate the needs of each resident. This can sometimes mean that some residents may require more physical care than others. As a result, HCPs often have to compromise their own internal values of wanting to provide equal amounts of care and attention to each resident on the unit. However, circumstances dictate that inevitably, some individuals will require more physical care than others. Therefore, it is understandable and logical to prioritise individuals in terms of how much physical care is needed for that person at that given time, especially in emergency cases.

Carter et al. (2017), explored GP perceptions of the barriers and solutions to good quality palliative care in dementia. They discovered five main barriers to providing good quality palliative care in dementia, these included:

The lack of dementia knowledge and understanding by health care professionals, family and the public; the limited resources and heightens pressure within the GP practice and in the community; the mismanagement of appropriate care provision; the

poor interdisciplinary health care approach, and finally the resistance and disagreements from families and patients (Cater et al., 2017. p. 24).

The solutions proposed to resolve these barriers were largely focused on enhancing education, training and considering the importance of family involvement. The improvement of public awareness was stressed as a vital element contributing to achieving good quality palliative care in dementia. However, further research would be required to determine whether the views expressed by GPs are replicated in the wider population - for example, in dementia care services and health care practices. The implications of my study also addressed the importance of enhancing dementia training in the future. For example, Stacey discussed the involvement of interdisciplinary teams in the context of a dementia care setting. She explained how a combination of support is required from all parties in order to achieve good quality care for those living with dementia. Stacey also highlights the importance of the GP's contribution to an individual's care and highlights the role of medication in dementia care practice, as she believes these factors can improve lives. However, Stacey pays attention to the importance of family involvement in dementia care facilities and addresses how she feels dementia residents require more GP input. Carter et al. (2017), explains how there is pressure on the GP community due to a lack of resources, as a result, demonstrating the organisational conflicts faced by both HCPs and GPs. This perhaps indicates how GPs and HCPs are in agreement with one another, in terms of addressing a need for change, yet sharing an awareness towards issues concerning the lack funding in current day health care services.

Carter et al.'s (2017), findings are specific to those currently living in residential dementia care as they are current and relatable to all parties in health care. i.e., doctors, families and health care staff. They raise the need to explore the applicability of these findings to the broader contexts in health care as a whole. The results also demonstrate how inter-disciplinary relationships in dementia care are an influential factor which can change a person's experience of care. Ultimately, implying that having good quality client-caregiver relationships helps to improve the overall quality of care provided.

Furthermore, the current findings contribute to the knowledge in the area of phenomenological research in health care, specifically, dementia care. The four superordinate themes:

1. Trying to remain positive: 'glass half full in all situations.'
2. Experiencing variety: workdays, individuals and reactions.
3. Emotional intelligence: caregivers experience suppressing their own emotions and maintaining the human relationship.
4. Growth aspirations: developing self as a caregiver through the experience of time.

All appear to arrive as core elements contributing to the experience of client and care-giver relationships in dementia care. It is evident that relationships are a valuable aspect of dementia care having important implications not only on the well-being of the residents but the staff also. These themes identify HCPs thoughts and feelings towards the way they care for individuals living with dementia and highlight some of the key limitations to developing caring relationships. It is important to highlight how the use of interpretative phenomenological analysis has aided in developing these themes and the aims of this research would have been difficult to achieve with an alternative method. This is because the results have offered some personal insights on how the participants feel about the experience personally. This level of detail would have been difficult to gather by using alternatives such as surveys and questionnaires etc. It also offer insights into the participant's real world views on what they believe necessary for improvement. Ultimately generating some discussion regarding implications for practice.

Relating Findings to Practice

The findings generated discussions concerning areas of practice which would benefit from future research and investigation. The main concerns raised related to areas including the influence of time, training and staff-wellbeing. These all arrived as core elements of associated with the experience of caregiving relationships in dementia care. This was demonstrated in

the participant's responses in interviews. Specific implications for research and practice are presented in Chapter 7.

Training

Stacey highlights how she believes that caregiving relationships will improve with training and attracting the right staff;

“Erm I think if the training improves, and I think if every dementia unit, I think, erm, if, if they attract the right staff, I don't particularly go for educated girls, I go for girls with a nice personality and a sense of humour” (Stacey, transcript 4, p.169, line 190).

Similarly, Catherine explains how dealing with situations at work are improved with time and practice, and experience;

“I definitely think the longer you have done it, the better you are with it, like, people who have worked with it for quite a long time can handle situations a lot better, it doesn't seem to stress them out at all, whereas people, new members of staff who never crossed dementia before and they don't understand it as much, sometimes don't understand what they're doing, are not very calm when they handle things, and can panic” (Catherine, transcript 2, p. 143, line 73).

These examples, though different in context and content, indicate some directions to future improvements in this particular area of practice. Also, paying particular attention to how to train newly qualified HCPs. To myself, it appears that the role of caregiving is somewhat of an 'on the job' and 'hands-on' learning experience for these participants. For instance, Catherine, in particular, explained how she found handling situations in the initial stages of becoming a caregiver somewhat difficult. She highlighted how Alzheimer's Society UK has increased the awareness of dementia over time. However, it would be feasible to suggest that perhaps the concerns lie more in the readiness to handle difficult situations, behaviours and management of time as opposed to the relationships themselves.

Time

Participants explained how 'time' was an essential element of the experience of caregiving relationships. Most participants agreed that getting to know the individual on a personal level

was the best way to care for someone living with dementia, however, there were often occasions where lack of time prevented this.

For example, Samuel discusses how he thinks person-centred care is a great idea however realises that time can often conflict this;

“I think it’s a great idea, but a lot of it doesn’t always happen, there only ever so much time in a shift and only certain amount of time to do certain tasks like you can’t not get everybody up, you can’t not feed everybody, those things have to be done, then, unfortunately, person centred care sometimes falls by the waist side, it shouldn’t do, we don’t want it to, but when you have only got so much time in a day” (Samuel, transcript 1, p. 137, line 245).

Similarly, Catherine explains some of the consequences concerning not having enough time to interact with residents, which is particularly relevant in regard to how someone living with dementia might react to a lack of time on behalf of the staff;

“I think some, when that attentions not there, they find other ways to get attention, you know they get bored sat there, they obviously want to do something, but that can cause problems, and is a bit much to handle, erm” (Catherine, transcript 2, p. 150, line 239).

Furthermore, Masie expresses how she feels time influences the residents, yet expresses her opinions towards staffing levels for dementia care;

“I don’t think the staffing levels are fair at all for dementia because some of them do take time, working in a place like this, you know there are only 12 residents, but even when there’s just three staff on, I don’t think it’s enough, you need time with them, you know to make them happy” (Masie, transcript 3, p.160, line 212).

These examples display the participant’s individual values towards time, making references to how a lack of time can affect, not only the HCPs experience of caregiving relationships but also, the residents. Time appears to be held as a valuable element of the caregiving relationship which is evident in all participants’ accounts. This is particularly important when considering the research aims of this project. The study specifically aims to understand how HCPs lived experience of working in dementia care environments, impacts on professional caring relationships between the resident and caregiver. Therefore suggesting that further

research into the effect of time on caregiving relationships would benefit implications for future practice.

For instance, it would be professionally important to consider just exactly how much 'one to one' time is deemed appropriate for residents living with dementia whilst exploring how HCPs address the issue of having insufficient time. Claims made by most participants would support this suggestion as they all agreed that getting to know the individual/resident on a personal level was meaningful to the participants in their role as a care-giver.

As an illustration, Stacey, in particular, highlighted how part of the experience of getting to know each and every resident individually was beneficial in practice, as it gives you the knowledge to prevent difficult situations and behaviour, which is considerably more important given the nature of dementia itself.

Additionally, it is interesting to note how the concept of time was perceived on two completely different planes. One being that time was vital in getting to know the individual in order to improve the quality of care being provided. Secondly time was professed as a factor which occasionally held individuals back in a sense of not having enough time to carry out tasks within a shift.

Staff-wellbeing

It appeared that most participants tended to portray themselves as having a can-do approach to care and tend to work in the moment taking each day as it comes. Most participants shared how they felt the emotional demands which came with the job.

HCPs in dementia care are faced with residents' emotional traumas on a day to day basis, whether it is anger, sadness, illness, or loneliness. HCPs are expected to express empathy and handle other people's emotional needs regularly. Interestingly, Portoghesi et al. (2020), discusses how health care professionals who work in emotionally challenging contexts are vulnerable to compassion fatigue. They define compassion fatigue as "a state of tension and

preoccupation with traumatised patients by re-experiencing the traumatic events, avoidance/numbing of reminders and persistent arousal associated with the patient” (Portoghese et al., 2020, p. 2).

However, most participants explained how they were mindful and confident in their abilities to handle emotions and situations effectively. Yet opinions on handling situations were assigned to factors such as age and experience. As a result, bringing me to some further queries for future research. I found myself questioning whether it would be thought-provoking to explore the extent to which emotional support was available to caregivers in dementia environments and whether there is a need for it.

Questions such as; how psychologically prepared are newly qualified HCPs to deal with the demands of the role? Would providing emotional support for caregiving enhance caregiving relationships in dementia care?

The ability to handle stressful situations could stem from current generational changes. We currently live in a time where we are encouraged to actively speak out about our emotions and not to be afraid to seek help with problems. A time where mind-sets, beliefs and values are changing and the increased awareness of mental health issues encourages well-being. Whereas, older generations' attitudes towards life were perhaps very different. As an illustration; the stiff upper lip culture metaphor. Historical shifts in mental health perceptions is something literature has previously considered. For example, Currin et al. (2011), explored the impact of age, historical change, and gender on perceptions of mental health and mental health services. Their study expected older adults to have less positive mental health perceptions than younger adults. However, they highlighted a positive historical shift in mental health perceptions, yet concluded that education about the benefits of mental health care is still needed. More recently, Meilach (2018), talked about the struggles of talking mental health with older generations. She discussed how there is difference in approaches to mental health between generation X and generations Y. This is particularly evident when most participants agreed that handling situations effectively was dependant on factors such as age and

experience, with this in mind, it would be beneficial to figure out new ways to address these differences in practice in a way which is suitable and inclusive to all involved, as it appears that perceptions towards mental health in the workplace is still a matter that currently occurs. Therefore, it would be feasible to suggest, that perhaps training for new younger HCPs may need to reflect changed cultural values in terms of emotional openness.

Accordingly, in a world that is continually moving with the times, so to speak, would it be beneficial for newly trained HCPs to take part in psychological training or whether there is a need for it given the time we currently live in as a means of connecting, attracting, and appealing to younger staff in a way which reduces pressure and burnout?

Burnout syndrome (BOS) has often been reported by staff members working in the health care profession (Quenot et al. 2012). Characteristic symptoms of burn out syndrome include; insomnia, headaches and fatigue. These are often a result of factors such as communication matters between organisational structures such as doctors, nurses, etc., or important decision making for the end of life patients. Ultimately, burn out can create consequences such as high turnover rates, diminished quality of care and the cost of absenteeism.

Quenot et al. (2012) evaluated the effectiveness of introducing an intensive communication strategy on BOS amongst caregivers working in intensive care units. Their findings illustrated that the implementation of an intensive communication strategy regarding the end of life decision was linked with a reduction in the relative risk of BOS. However, on evaluating the level of suffering measured by burnout and depression, they concluded that further study would be needed to explore the factors that source suffering in the workplace.

Quenot et al. (2012), also agrees that burn-out is something that exists within the health care environment, though this is not specific to dementia care environments, which the current study focuses on, after reflecting on the participant's accounts I come to understand that workplace stress has affected many of these participants. They indicate some clues related to factors which perhaps contribute to handling stress in the workplace, however, in agreement

to Quenot et al. (2012), more research is required to understand the extent to which factors such as age and experience actually influence stress in the workplace.

Quenot et al. (2012)'s findings are specifically applied to the reduction of stress when making end of life decisions, it would be beneficial to conduct more research to discover whether the implementation of an intensive communication strategy would be beneficial to wider aspects of the care-giving environment and more details on what this strategy entails and how it would be applied. Questions such as who will be using this strategy? Will this information be made available to all HCPs? Or even looking into why communication is becoming an issue in the first place, by perhaps understanding people's opinions and experiences of how communication and stress relate to one another.

Similarly, the stress of conscience, formerly defined as stress caused by a troubled conscience, is perhaps a further notion associated with workplace stress (Glasberg et al. 2008). The current study's findings reveal examples where stress of conscience is something participants have experienced. This is particularly evident when participants discussed their desire to work in a person-centred manner, however they experienced occasions where they are not able to work this way because of organisational barriers such as levels of staffing. Additionally, stress of conscience is also likely to occur in environments where employees' age, gender and experience are diversified. This is because there is a variety of different opinions and abilities to cope with stress (Orrung et al. 2015). These studies relate to the current study and relationships in dementia care. Most participants agreed that at some point in their career they found themselves experiencing stress and taking matters home with them. Which explains with time you become more acclimatised to dealing with situations more effectively. Through it would be useful to research ways to reduce such factors, which in turn, leads to more effective and high-quality care for those living with dementia.

In particular, I would like to reflect on how this study has drawn attention to a range of perspectives not only to do with the lived experience of caring relationships in dementia, as addressed in the proposal but also discovering more organisational and personal perceptions of the experience; which I feel are all closely interlinked and equally as justified to the overall development of relationships in dementia care. This idea is eloquently summarised by Eatough and Smith (2006 p. 484) who stated that: "Emotion experiences are often world-focused rather than self-focused; they are directed outwards towards the world, and the people and events and objects that make up that world".

To elaborate, many of the participants experienced relationships on a multitude of levels. PCC was influenced by many different factors. For instance, differences in caregivers' individual personality and attitudes tended to affect the HCPs views towards caregiving relationships on the unit. Also, time influenced the quality of relationships, meaning the practice of PCC was dependant on how much one to one time was available with residents. A lack of time was professed as a factor associated with organisational influences, such as staffing levels.

Additionally, influences such as experience, training and personal strength when dealing with difficult situations affected the overall caregiving relationship between resident and care staff. Similarly, the emotions they experienced are often a result of 'world-focused' issues directed at their surroundings rather than 'self-focused'. For instance: the feelings of having to suppress personal emotions, like grief and loss, are generally ignored by staff due to an awareness that emotional detachment comes with the job role. Realistically, grief and loss is expected due to the nature of dementia (as there is currently no cure for the disease), therefore, staff will be expected to not let these feelings affect them. This appears to be a product of a workplace culture where these particular attitudes are perhaps distilled in many HCPs when entering the

field. However, participants in the current have addressed instances of feeling somewhat opposite to this particular notion but they have the ability to bracket these feelings, which is a skill in itself.

As a result, after analysing the participant's responses, it was interesting to consider how emotional intelligence was experienced by participants. Most participants spoke about how they have an awareness of the reality of being in a dementia care environment and therefore make sure they do not become attached to residents. However, they also appreciated that this was not always easy. Ultimately, this indicates that attempts are made by the participants' to keep caregiving relationships close to the human relationship thus revealing the nurturing nature of the caregiving role.

On reflection of the method, I believe use of semi-structure interviews allowed my participants to speak openly about specific experiences with no restriction on their responses. Similarly, I feel they were useful in having the flexibility to venture between different areas of conversation allowing the participant to have control of what they chose to talk about. This seemed appropriate as the purpose of the interviews was to reflect their own personal experiences. Therefore the participants were able to talk freely about things that mattered to them, whilst still incorporating some structure of discussion throughout the interviews. However, looking critically, I would also have suggested that these interviews would perhaps have been more in depth if they were slightly longer; allowing more time for thought and reflection. The realities of interviewing in the home meant interviewees were constrained by the time demands of their work. This in itself helps illustrate 'time' as a key theme in the research.

Retrospectively, I do feel the data collected was sufficient enough to explore the phenomenon effectively providing some conclusions for further study. With respect to the question designs, I feel there may have been times whereby the interviewee may have misheard the question, or asked for me to explain the question further, which is no fault of my own and something that perhaps can be more thoroughly practiced and worked on in future studies.

Interviews as a research methodology have long been a topic of debate between philosophers and social theorists. Some of the main criticisms are concerned with the problems of representation, the nature of language, the problems of writing and the inseparability of researcher and knowledge (Peters & Halcomb, 2014). One could argue that there may have been some questions regarding having an insider as a researcher. Therefore, in an attempt to remove any misconceptions I explained prior to interview that they should imagine that I had no prior knowledge or understanding of the field in discussion, as I also worked in the a HCA. To some degree this was beneficial in helping the interviewees understand the aims of the research and why it was important for me to remain impartial in the discussion and not influence the respondents in their views. Although, naturally one can understand the difficulties of fully achieving this objective, as it unnatural to pretend you do not know someone, therefore elements of the interviews did show there were a relationship between the researcher and interviewee. However, on reflection this may have made the participants feel more comfortable to speak about the experiences as there was some familiarity.

To summarise, these findings offer a detailed insight into the experience of caregiving relationships in dementia care, contributing a variety of different perceptions and experiences in the dementia care setting. Many of the participants indicated having an attitude of immediate positivity which was a major factor contributing to the well-being of the dementia residents and handling potentially negative situations. The use of humour was spoken about by participants and it appeared to me that small acts of kindness and sense of humour strengthened relationships with the residents and also staff members. Additionally, most participants experienced a sense of variety in all aspects of the experience of care-giving relationships and highlighted a philosophy of 'expecting the unexpected'. Participants experienced a variety in both their workdays and the individuals which they were caring for, not forgetting the degree of personalised care required for each resident. Many expressed that having an awareness of how to react to different individuals was a key factor related to the job role.

Overall, the study has demonstrated how the research findings have addressed the original research questions;

- ✓ To gain a rich understanding of Health Care Professionals perceptions of client and caregiver relationships in residential dementia care.
- ✓ To understand how Health Care Professionals lived experience of working in dementia care environments impacts on professional caring relationships between the resident and caregiver.

I have made attempts to outline how the current findings compare to the research which is already available and relevant to relationships in dementia care. I would like to pay attention to key elements such as 'time', 'training' and 'staff wellbeing', which point to future areas of research worth exploring further, contributing to reasons why dementia care practice and policy would benefit from paying more attention to these key areas of research. This final chapter will also outline future implications for caregiving practice and research with reference to the study's findings. Suggestions for future research in the area of caregiving relationships in dementia care will be built upon the interpretations already made through the lens of Interpretative Phenomenological Theory.

Summary of the strengths and limitations of study

The use of IPA allows for an in-depth account of all aspects of experience to be considered when generating implications for future research and practice. This method has allowed meaningful interpretation to be made, which are specific to the participants' experience. Having an understanding of how HCPs experience their work is important for policy makers and other organisations running dementia care facilities as the deeper knowledge of their experiences could provoke motivation for improvements. The experience and perspectives retrieved from the data collection are limited to the perspective of only the HCPs from one dementia care unit in the U.K. therefore, the themes generated would require an extensive

investigation to a wider population in dementia care. Despite this, the method has allowed the researcher to get close to the real world experience of HCPs, providing insight on how they operate daily and the use of purposive sampling allowed inclusion of a diverse sample. In this case, age, gender and length of health care experience. Although, it would require further research to clarify the implications generated from this research, perhaps by broadening the sample to incorporate HCPs from alternative providers such as domiciliary health care backgrounds.

The experience of the phenomena may actually be beneficial during the interpretations of the results, as empathetic understandings may come more naturally when the individual also has the first-person experience of the phenomena. Therefore in the process of collecting meaningful data, interpretations are more carefully made, due to the awareness of the phenomena. The study is inevitably restricted to the perspective of interpretations made by me as a researcher who also works in dementia care. It is perhaps feasible to suggest that inevitably, my personal feelings towards the topic are often difficult to bracket, regardless of the steps taken to remain impartial. However, future research needs to take place perhaps from an outsider perspective allowing for contrast in interpretations and variety in Chapter 6.

The location of the interviews often took place during the participants shift as this was the only opportunity to utilise their time. More detailed interviews may have been obtained if they took place outside of the workplace, where there was more time available to explore some of the interview questions further. Therefore the execution of the interviews perhaps needed more management in terms of planning.

Implications for Research

The findings from the current study imply that training is an area that would benefit from future research and improve the quality of relationships in dementia care. Much support for this can be seen in the participants' accounts throughout the study. Most participants agreed that a

positive future for caregiving relationships would require the improvement of training in dementia care. Additionally, the current findings indicate that training could be explored from a variety of angles. For instance, Catherine highlighted how in her early days of becoming a caregiver she noticed she used to panic a lot. Although in her case she overcame this with time and practice in the role, it would be useful to investigate the 'how' and 'why' caregivers may be panicking in the first place and establish whether training plays a factor in this. If so, future research could question whether there are new ways of training HCPs so this can be prevented in the future.

Furthermore, in an era and generation where imaginably 'time is money', the results therefore stimulated some enquiry regarding future research into how dementia care professionals are being trained currently. It would be interesting to discover how alternative care-providers, outside of the residential and private sector of care, experience training in a dementia environment. This could be achieved by gaining an understanding of some of the opinions and thoughts that HCPs might have towards training, and also look at new innovative ways to strengthen client and caregiver relationships through training. For example, Benbow et al. (2019), discusses the relevance of relationships to health and social care, highlighting how education of health and social care should include the relational impacts of dementia. They explored the changes in family relationships associated with dementia from the perspective of those living with dementia and their caregivers. They suggest how research is needed into ways to of supporting relationships. They consider whether counselling could play a vital role in care planning, implying how it could potentially benefit the person with dementia, their caregiver and other family members.

Implications for practice

All participants were optimistic about the future of caregiving relationships but showed rationality in their understanding of what was presently holding back growth in the future.

However, the results of the current study demonstrate how the optimal environment for effective caregiving relationships is made possible in a place where the staff have enough time to tend to the needs of the residents in a person-centred manner whilst completing the tasks necessary. A place where emotional demands of the role are supported and the physical demands of the job are manageable.

To support this statement, Li and Porock (2014), discuss resident outcomes of person-centred care in long term care. They highlight ways to alleviate factors which hinder quality of life in organisational care settings, such as, loneliness, helplessness and boredom. Their small house model, also known as the green house project, aims to promote person-centred care through drastic transformations of the physical environments. In the current study, participants have noticed that residents perhaps experience boredom in the home and this happens when there is a lack of attention. They highlight how the lack of attention can sometimes lead to negative circumstances. This empathises the importance of needing to address ways to alleviate factors which hinder the quality of life in care settings, as a lack of resources (in this case staffing levels) can disrupt the environment for the residents. However, despite finding that culture change models, such as above, have some beneficial effects on psychological well-being in long term care. They, however, acknowledge how person-centred dementia care requires replication in order to confirm these finding in a dementia care context.

Retrospectively, after comparing all participants' accounts of the experience of care-giving relationships in dementia care, it appeared there was perhaps a workplace culture revolving around the nature of to 'roll with punches' with a person centred ethos. Nonetheless, most participants explained how they believed the newer and younger staff perhaps struggled with handling situations more than individuals who had the most experience. My questions lie with the thought of whether it is appropriate to address new ways of training, helping and encouraging newer caregivers to become better equipped to confidently handle difficult situations as effectively as perhaps a more experienced member of staff would. Examples of training could include, subjects such as teaching new HCAs how to balance clinical

detachment and empathy to optimise the care for each resident. Incorporating some elements of stress awareness and how to handle stress effectively. Although the need for these additional types of psychological training for HCAs would need further research to a wider population in order to establish the need for them.

Toit et al. (2019), would support the idea of introducing new ways of training as their research focuses on peer-enabled training as a means of promoting person-centred dementia care. They believe that person-centred care is regarded as the best practice within dementia care, but that there is a gap between the academic understanding and the implementation of this type of practice practically. Similarly, most participants agreed, that the best approach to dementia care was the use of PCC, however they expressed scepticism towards future improvements of PCC due to the lack of money in the system. This demonstrates the need for further research in order to assess the long-term sustainability of potential advances to person-centred care.

Overall, this research ultimately deepens our understanding of how working in a dementia care environment, impacts on caring relationships between the resident and caregiver. The overall findings of this research are valuable and could be beneficial to health care practices and future research through publishing and peer review. They could also be made available to the populations who may find them helpful, such as, dementia charities, specialised dementia unit's, and home care facilities. The findings and literature discussed in this research are grounded in a fundamental motive to strengthen relationships in dementia care. Motivation for improvement on behalf of the HCPs appears to be key factor associated with the experience of relationships in dementia care. Finally, further research is necessary to build on these interpretations and evaluate to what extent these factors discussed are associated with time, training, and staff wellbeing and establish whether these findings will eventually contribute to the improvements of relationships in dementia care practices in the future.

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PARTICIPANT CONSENT FORM

Project Title: 'Client –Caregiver relationships in Dementia Care: The experiences and perceptions of Health Care Professionals'

Researcher: Megan Nicola Downes Bsc (hons) | Post Graduate Researcher | Human and Health Sciences |

Organisation: The University Of Huddersfield

Thank you for your interest in this project. Before agreeing to participate, please read the information sheet. If you have any questions, please ask a researcher. You will be given a copy of this consent form, and one will be retained by the researcher.

I have read the information sheet and understand the purpose of the research.

I understand that if I decide to no longer take part in this research I can leave the

Interview at any time. I understand that I can withdraw my data any time prior to publication.

I understand that should I wish to withdraw my contribution I can contact the researcher before the withdrawal deadline on the 1st June 2019, without giving a reason.

I understand that my personal information will be processed only for the purposes of this research. I understand that such information will be treated as confidential, except where legal obligations require information to be shared with relevant personnel, and handled in accordance with the provisions of the General Data Protection Regulation (GDPR) and UK Data Protection Act 2018.

I understand that the information I share, including anonymised direct quotes, may be included in any resulting report.

I consent to the research team having access to any results derived from this study for any subsequent analyses or publications in the future. I understand that any identifying information would be kept confidential (except where legal obligations require information to be shared with relevant personnel), and access limited strictly to the original study team and database team.

I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

I understand that my participation will be audio [OR VIDEO/PHOTOGRAPHED] recorded for accuracy.

I understand that any audio recordings may be transcribed by individuals other than the research team.

I understand that data provided may be shared with researchers in countries outside the European Union.

I understand that the information I provide will be retained for 10 years at the University of Huddersfield and destroyed.

You as a participant have the right to access and modify the data if you feel you would like to reiterate a particular phase or add in extra information regarding a particular interview question. Furthermore, a receipt of interim findings is available at your request.

I agree that the project named above has been explained to me to my satisfaction and I agree to take part in this research.

I have read and understood the University of Huddersfield's Privacy Statement and consent to the researchers processing my personal data accordingly.

<https://www.hud.ac.uk/informationgovernance/dataprotection/>

Please read and complete this form carefully by ticking the statement you agree with on the right hand side of the bullet point.

-
- I have read and understood the information sheet provided regarding the aims and objectives of the research.

- I am aware that the interview will last around 60 minutes and I agree to be asked a number of questions regarding my experience of working with individuals living with dementia, in residential care facilities.
- I consent to my answers being recorded/ transcribed for further use by the researcher only.

- I do not anticipate any inconveniences or risks resulting from this research. However, if at any point there are any questions proposed to you during the interviews that cause discomfort you are free to refuse to answer them or leave the interview process without reason.
- I am aware that I can be debriefed at the end of the interview if you feel it is necessary. I can request a follow up report on the results of the research by contacting the researcher by email.

- I understand my participation is voluntary. Refusal to participate or withdrawal of your participation in the study will not result in any negative inconveniences.
- The results of this research will be presented anonymously. I understand you will be identified by occupation due to the nature of the research however my personal identity remaining disclosed.

- I understand the research will not disclose any information of organizational bodies and the company I work for will not be mentioned in the research.
 - I understand that completed data will only be available to the researcher and two supervisors assisting with the research. Data will be stored on a secure password protected document at the University Of Huddersfield for 10 years.
-

- I understand that The University of Huddersfield's School Ethics Research Panel (SREP) has approved the procedures for this research.
- I am aware and agree with the limits of confidentiality. Which have been explained to me in the information sheet.

'Quotation Agreement':

I also understand that anonymised quotes from my interview may be used in publications and presentations arising from this research.



Please tick the following statements you agree with (place a tick next to the bullet point on the right hand side:

-
- I wish to review the notes, transcripts and other data collected during the research pertaining to my participation.

- I agree to be quoted directly as long as my name is not published and a made up name or number is used instead.

- I agree for my occupation as a health care professional to be used when quoted.

- I agree that the researcher may publish documents that contain quotations by me.

PRINT NAME:

SIGNATURE:

DATE:

Interview Schedule

Start by introducing myself and thanking the individual for their participation.

- Then explain the process – using the information sheet, asking if they understand everything on it. Get the participant to read and complete the consent form.
- Ask if they have any questions before the interview begins. Reassure that the participant is comfortable and ready to begin.

Questions may not flow in the running order of the schedule – researcher can pick up and explore interesting comments about the experience that may arise.

- I know I work with you all and I can already imagine the answer to this question. However, let's imagine I was a completely new to meeting you. Could you let me know how you came to be a Health Care professional?
- What is a typical working day like for you?

Perhaps paraphrase something they have said which may follow onto the next question

- Could you please describe/explain what type of, or what clients have you worked with during your time at this care home?'
- With this in mind, could you describe your understanding of Dementia perhaps explaining how this might impact your typical day?

Prompts – Workload, disruption to routine, stress

- Could you tell me about some of your experiences positive or negative, about working with your client with Dementia?

Prompt – Remind participants they don't have to mention any names etc.

- How does it make you feel when you are dealing with these particular challenges?

Prompt – physically, emotionally and mentally?

If they talk about emotional, physically stress etc.? Perhaps empathise with the participant.

- As a Health Care professional, are there often times you feel like these particular stressors – impact you out of work?
- What do you think about maintaining good relationships with your residents in the home? What does it mean you?

Prompt – is it important you?

- I understand every relationship is going to be different, but how would you describe your overall relationship with the residents, in your own words?
- How do you think your relationship with the residents on your unit affects your typical working shift/day?

Prompt- stress levels, communication, work load

- Can you talk to me about a particular time you felt your relationship with a resident has been positively or negatively impacted by certain circumstances out of your control as a care giver?
- Can you talk about your experiences which you found to be satisfying in terms of your own care for Dementia clients?
- When would you be particularly satisfied with your work?
- If you had to describe what the ideal relationship with a Dementia patient means to you? What images come to mind?
- How would you describe yourself as a care-giver?
- What was it like when you first started working with individuals living with Dementia?

Prompt – relationships? Easy? Difficult?

- How are your relationships different as opposed to when you first started working with Dementia residents? What's changed?
- Has your personality made a difference to how you form relationships with Dementia patients?

Prompt: if so, what advice would you give to a new comer in respect to forming relationships with a Dementia resident?

- What are your opinions on person centred care?

Prompt; do you think the principle of person centred affect caring relationships? If so how?

- What do you think are the main issues that affect the relationship between care-giver and patient?
- What do you think of current government policies regarding care for those living with Dementia?

Prompt; Mental capacity Act, Person centred care practice

- What do you think care practice will be like in another 5-10 years from now? Especially for those living with severe Dementia?

Prompt; Relationships? Improve? The rise in Dementia prevalence? Economic impact of Dementia. Public Perception? Awareness etc.

- Depending on their answer, which of these factors do you believe will affect the relationship between care giver and Dementia patients and you opinions around these factors?
- Finally, what do you think relationships will be like between care giver and Dementia patient in another 5-10 year times?

End by thanking them for their participation and their time, explain how it's been lovely hearing about your experience etc.

THE UNIVERSITY OF HUDDERSFIELD
School of Human and Health Sciences – School Research Ethics Panel

APPLICATION FORM

Please complete and return via email to:

Kirsty Thomson SREP Administrator: hhs_srep@hud.ac.uk

Name of applicant: Megan Downes

Title of study: 'Health Care Professionals perceptions on the importance of client and caregiver relationships specific to Dementia Care': An Interpretative Phenomenological Analysis.

Department: Human and Health Sciences FT

Date sent: 20/11/2018

Please provide sufficient detail below for SREP to assess the ethical conduct of your research. You should consult the guidance on filling out this form and applying to SREP at <http://www.hud.ac.uk/hhs/research/srep/>.

Table 4 –Ethical approval

| | |
|---|--|
| Researcher(s) details | U1457314 |
| Supervisor(s) details | Kagari Shibazaki And Nigel King |
| All documentation has been read by supervisor (where applicable) | YES / NO / NOT APPLICABLE This proposal will not be considered unless the supervisor has submitted a report confirming that (s)he has read all documents and supports their submission to SREP |
| Aim / objectives | <ul style="list-style-type: none">•To gain a rich understanding of Health Care professional's perceptions on client and caregiver relationships in residential Dementia care.•To understand how Health Care Professionals lived experience of working in Dementia care environments impacts on professional caring relationships between the resident and care giver. |
| Brief overview of research methods | Qualitative Research method to be used. Interpretative Phenomenological Analysis. Six interviews with Health Care Professionals with a background of Dementia care. Semi structured interview questions to be used. An IPA analysis to be conducted on interview transcripts. Identifying major themes which arise in the data. Discussion of results found. |
| Project start date | 17/09/2018 |
| Project completion date | 17/09/2019 |

| | |
|---|---|
| Permissions for study | Verbal Permission will be need from Participants and Supervisors and care home manager. I have personally spoke to the staff members on the unit I work on asking if they would be interested in participating in the research. Information sheet provided and copy of proposal offered if they wish to receive more information regarding the research. A consent form and Information sheet will be provided to the participants. |
| Access to participants | I currently work on a Dementia Unit as a Senior Care Assistant; therefore I have access to Health Care Professionals within the Residential Care Home. I have worked here since May 2018 and my colleagues have agreed to participant in the research though me talking to them about my studies and personally asking if they would be interested in participating. |
| Confidentiality | Information gathered in interview will be confidential. The recorded data from interviews will be stored on a secured password protected hard drive at the University of Huddersfield. Consent Forms will be stored in a safe file. Any recorded data can be requested or destroyed if requested so by the participant. |
| Anonymity | Participant's names will not be used in research. The Care home name will also be unidentifiable. They will be identified by occupation; permission for this will be required on behalf of the participant. All the personal information including organisation are not mentioned in the final write report. Participants will sign a quotation agreement which gives permission to quote their words in the final report. |
| Right to withdraw | Participants will be given the right to withdraw at any given time. This can be before, during or after the interview. They do no need to give reason for withdrawal. In the event of the final write up if a participant asks for their data to be removed this will be done with no question and their data will be destroyed. I will ask participants to withdraw from the write up by the 1 June 2019 which allow time for a further participant to be recruited. |
| Data Storage | Password Protected Document on Huddersfield University Hard Drive. Data could be stored for 10 years after the completion of the study, unless ask to remove by participant. |
| Psychological support for participants | If the participant is upset or depressed after the interview, they can contact me or my supervisors to discuss any issues they may have faced as a result of this study. A debrief can be provided in this instance. Participant can be put in contact with appropriate contacts if in the unlikely event they do suffer any psychological harm from the interviews. For Instance, NHS services, Charities and helplines. |
| Researcher safety / support (attach completed University Risk Analysis and Management form) | Risk Management form has been completed and attached. |
| Information sheet | Information regarding research will be provided to participant prior to interview. Participant will be asked to read this before reading and signing the consent form. |

| | |
|---|--|
| Consent form | All Health Care Professionals will be required to sign a consent form before participating; having a full understanding of what is required from them as a participant. |
| Letters / posters / flyers | No - Verbal permission from home manager. Permission granted from home manager. I inquired about writing a letter but I was informed that that was not necessary as long as I have the permission from the participants. |
| Questionnaire / Interview guide | Semi- Structured interviews- Draft was developed following IPA guidelines. I also used concepts from person centered counselling practice techniques. E.g. Use of paraphrasing, Empathy, summarising. |
| Debrief (if appropriate) | N/A |
| Dissemination of results | Participants can contact me via email if they wish to follow the research. I work with the majority of participant wishing to take part so they can contact me via mobile or on shift. |
| Identify any potential conflicts of interest | N/A |
| Does the research involve accessing data or visiting websites that could constitute a legal and/or reputational risk to yourself or the University if misconstrued? Please state Yes/No If Yes, please explain how you will minimise this risk | No |
| The next four questions in the grey boxes relate to Security Sensitive Information – please read the following guidance before completing these questions: http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/oversight-of-security-sensitive-research-material.pdf | |
| Is the research commissioned by, or on behalf of the military or the intelligence services? Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data | No |

| | |
|---|----|
| <p>Is the research commissioned under an EU security call</p> <p>Please state Yes/No</p> <p>If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data</p> | No |
| <p>Does the research involve the acquisition of security clearances?</p> <p>Please state Yes/No</p> <p>If Yes, please outline how your data collection and storages complies with the requirements of these clearances</p> | No |
| <p>Does the research concern terrorist or extreme groups?</p> <p>Please state Yes/No</p> <p>If Yes, please complete a Security Sensitive Information Declaration Form</p> | No |
| <p>Does the research involve covert information gathering or active deception?</p> <p>Please state Yes/No</p> | No |
| <p>Does the research involve children under 18 or participants who may be unable to give fully informed consent?</p> <p>Please state Yes/No</p> | No |
| <p>Does the research involve prisoners or others in custodial care (e.g. young offenders)?</p> <p>Please state Yes/No</p> | No |

| | |
|--|-----|
| Does the research involve significantly increased danger of physical or psychological harm or risk of significant discomfort for the researcher(s) and/or the participant(s), either from the research process or from the publication of findings? Please state Yes/No | Yes |
| Does the research involve risk of unplanned disclosure of information you would be obliged to act on? Please state Yes/No | Yes |
| Other issues | N/A |
| Where application is to be made to NHS Research Ethics Committee / External Agencies | N/A |
| Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy | |

All documentation must be submitted to the SREP administrator. All proposals will be reviewed by two members of SREP.

If you have any queries relating to the completion of this form or any other queries relating to SREP's consideration of this proposal, please contact the SREP administrator (Kirsty Thomson) in the first instance – hhs_srep@hud.ac.uk

Research Project Title:

‘Client and Care-giver Relationships in Dementia Care: The experiences and Perceptions of Health Care Professionals.

Research investigator: Miss Megan Nicola Downes BSc (Hons) (Post Graduate Researcher at the University Of Huddersfield)

Others who may be involved in this research: Dr. Kagari Shibazaki and Professor Nigel King.

About the Research:

The purpose of this research is to gain a rich understanding of healthcare professional’s perceptions and experiences on client and caregiver relationships in residential dementia care. We are interested in the health care professional’s views regarding the importance of relationships in dementia care. We ultimately want to understand how health care professionals lived experience of working in dementia care environments impacts on professional caring relationships between the resident and care giver.

At present, a significant amount of the current literature reports on studies related to the clinical and medical aspects of dementia. However, despite the improvements made on pharmaceutical medications which slow down the progression of dementia and alleviates symptoms, there is still no current cure for dementia and the prevalence of dementia is set to rise in the near future. With this in mind, we as researcher’s feel it is important to respond to current national policy regarding person centred care and continue to promote person centred care practices for those living with Dementia in the Uk. We aim to do this through research with the ‘relationship’ between client and care-giver at the focal point. Recent literature explores the idea of ‘relationship centred-care. My aim is to explore this with health care professionals, by exploring at the lived experience of relationships in every day practice.

Furthermore, by focusing on the relational aspects of dementia, paying attention to the ‘here and now’ so to speak, and ultimately highlighting the importance of the individual’s experience. We think it is important to explore health care professional’s current views, experience and reality of caring for individuals with severe dementia as those are the ones implementing the care, and contributing to their overall well-being.

Who is responsible for the data collected in this research?

Megan Downes (The Researcher)

What is involved in the research?

The research involved a 60 minute interview with yourself and me discussing your experience of working with residents living severe dementia.

What will happen with the collated research?

The interviews will be analysed as data and summarised in comparison to other studies and theories alike, with the aim to answer the initial research question.

What are the risks involved in this research?

Please do understand there are limits to confidentiality. If in the unlikely event I do feel you have disclosed any information to me which I believe will cause harm to either yourself or anyone else. I am obliged to breach confidentiality.

What are your rights as a participant?

Your contribution to this research will be kept confidential. You will only be identifiable by occupation. (Health Care Professional) There will be no disclosure of your governing body. You will sign a quotation agreement indicating your wishes in how you wish to be quoted in the research. The actual recording will

be kept on a secure password protected document at the University of Huddersfield and will be stored for up to 10 years. If questions arise which you do not feel comfortable to answer you have the right to refuse or withdraw from the interview

At any given time without any reason. If you feel you have experienced any psychosocial harm at any point of the interview, please contact the researcher and a debrief can be provided. Alternatively, in the unfortunate event you may need further help: the appropriate contact and helplines will be provided. A follow up report can be granted at your request. However, this research has received ethical approval from the University of Huddersfield SREP committee and do not expect any inconveniences as discussed. You have the right to withdraw at any given time, whether it is before, after or during the interview. If you feel you would like to withdraw after the study as taken place, please be aware there is a withdrawal deadline on the 1st June 2019. This is simply to allow for me to recruit a further participant.

What will be required from you, if you agree to take part? How much of my time is needed?

- Fill in a return consent form to researcher, either manually or electronically via email by (date to be included).
- There will be an interview which will last no longer than 60 minutes.
- A time, date and location will be set to meet when possible. I can travel to you, however if this is not possible then a time and date can be arranged on other means such as Skype/Facetime/Phone interview etc. Face to face interviews could be arranged outside of working hours or within depending on the nature of that particular working day.
- A copy of the final research thesis can be provided if requested. Additionally a follow up report concluding the results is also an option.

For more information

Please contact myself personally or via email which is provided.

What if I have concerns about this research?

If you are worried about this research, or if you are concerned about how it is being conducted, you can contact;

Megan Downes | Email: Megan.Downes@hud.ac.uk

Dr Kagari Shibazaki | Email: K.Shibazaki@hud.ac.uk

Professor Nigel King | Email: N.King@hud.ac.uk

University of Huddersfield SREP committee | Email:

THE UNIVERSITY OF HUDDERSFIELD: RISK ANALYSIS & MANAGEMENT

| ACTIVITY: Semi Structured interviews on six Health Care Professionals | | | Name: Megan Downes | |
|--|---|-----------------------|---|-----------------------|
| LOCATION: Residential Care Home | | | Date:20/11/2018 | Review Date: |
| Hazard(s) Identified | Details of Risk(s) | People at Risk | Risk management measures | Other comments |
| Psychological harm | Case sensitive conversation. Unaware of individuals experiences with Dementia, may be distressing for participant depending on past experiences. | Participant | Ensure research aims are made clear. Ensure fully informed consent. Offer debrief if required. | |
| Participant withdrawal | | Researcher | | |
| Harm to researcher | Participant may withdraw last minute. Meaning data collection will be either not possible or incomplete | Researcher | Ensure confirmation of participation on behalf of participant. Have back up participants willing to participate if one does withdraw. | |
| Uncovering evidence of dangerous practice or abuse | Lone worker- Carry out interviews within social hours and travel by public transport in social hours and somebody with know my arrangements at all times. | Resident/ Staff | Follow lone worker policy. If an interview has to be carrying out in someone home, keeping a phone and emergency contact. Ensuring people know where you are. | |
| | Participant disclosing information that means I am required to breach confidentiality. If you feel someone is in danger or a risk. | | Ensure limits to confidentiality are explained to participant. | |

1 [Appendix F- Transcripts from Interview](#)

2 **Interview 1**

3 **Researcher** –'so if I run through this you- it's your consent form, so basically this is what we
4 discussed... Yeah... so if you tick all the boxes which you agree with. Are you okay with that?

5 **Participant** 'yep'

6 **Researcher** 'Any questions?'

7 **Participant** 'Nope I don't think so'

8 **Researcher** 'Right so... obviously... me and you work together don't we - so when I ask you

9 these questions try and imagine you've never met me .. Yeah? And

Researcher explain how they wish to remain impartial, to remove the barrier or being colleges/conflict of interests. Etc.

10 I'm completely new to dementia - I don't know anything about it - so

11 - I told you all that. Where going to start with how you become a health care professional.'

12 **Participant** - erm I did it because, well I started at 23, I had a few years in jobs that I didn't

13 like, just in things like supermarkets and what have you, but I had have experience doing

14 voluntary work with kids, erm, only a little bit, in France, basically it's a pilgrimage it was

15 somebody I knew through the church my mum and dad go to, asked

Searching for job satisfaction

16 me to go. They take them to France, it's like a religious pilgrimage for parents and a bit of a

17 holiday for the children. And I got a lot out of that than any of the other jobs I had had. So I

18 decided to get a job that I actually sort of care about.

Participant talks about feeling satisfied with work relating to helping other. Perhaps more meaningful. The idea of doing something worthwhile/fulfilling. Explains how past experiences brought the participant to the current role they are in. Explains how didn't like previous job roles.

19 **Researcher**- yeah

| | | |
|----|--|---|
| 20 | Participant- It sounds a bit saccharine to me sometimes, well I was | Sense of embarrassment, but truth in what the participant was doing. |
| 21 | even embarrassed using that in my interview, but it was the truth. | |
| 22 | Researcher - yeah | |
| 23 | Researcher- So when did you start caring? | Appears to be in health care a long period of time. |
| 24 | Participant- well it was about 11 years ago | |
| 25 | Researcher- 11 years ago... Wow. I didn't know it was that long ago. Right - so you come into | |
| 26 | work, what's typical day like for you? | |
| 27 | Participant - well that depends if it a late or morning shift? | |
| 28 | Researcher- Let's say... you could do both? | Helping residents live their usual lifestyle. |
| 29 | Participant - Ah so all day then. It starts getting. Well your days is helping them get on with | |
| 30 | their day. So you'd start you'd get them up, people get up, erm the idea is that erm, when they | |
| 31 | need help you give them help, if they don't , if some can still do for | |
| 32 | themselves, encourage them to do so, you can point to the track of, | Participant explains how they help the resident live a usual typical day but providing help along the way. Also explain how they offer choice and encourage |
| 33 | say like, right look if this task needs done, let's get it done, it's not supposed to be the point is | |
| 34 | it, so the idea is that, if someone can get themselves dressed, or choose | |
| 35 | their own outfit, you kind of back off let them do it, or help them to | Makes a comparison to the day being similar to our own. Appreciates how their environment is different to the usual. The use of the work unfortunately indicates- that the participant is perhaps experiencing a sense of disappointment about the fact some residents are not able to do a lot of things. Highlights how this is a big negative. Provides an overview of the daily routine. Highlights again - the independence factor |
| 36 | do them things themselves. | |
| 37 | Researcher- yeah. | |

38 **Participant** - So we start, we get everybody up, all hygiene needs met, Trying to create a particular environment for the residents to live in. Familiarity

39 washed and dressed erm, and then its breakfast, and again it back off Offering choice - Person Centred Care.

40 let them. Hygiene needs met, choose their own means, let them Encouraging normality.

41 choose, erm, some people cant them choose dressed erm, needs met, washed and dressed erm,

42 off let them do it,e them help, if they don't , if some can still So basically you're trying to

43 replicate the sort of day you and me might have, you basically you're trying to replicate the

44 sort of day you and me might have, trying to simulate that really, erm Believes being involved in activities to hold some significance in care. Sense of disappointment by using the word unfortunately - empathy. Sympathises with the fact some residents are not able to do this,

45 it late that to replicate the sort of day you and me might have, help

46 them. When they don't, let them do it. let them if some can still do for themselves, encourage

47 them to do so, you can point to the track of, and some go to social therapy, some unfortunately

48 don't, and don't do a whole lot of anything and which is one the big negatives really.

49 **Researcher** - hmmm so (pause) you say you been there 11 years is it, so you have worked with

50 different types of people over the years not just dementia

51 **Participant** - yeah, erm 90- 95 per cent is dementia, I've always been on the dementia unit.

52 Erm.

53 **Researcher**- right Highlights the transparency of dementia. Perhaps difficult to detect sometimes.

54 **Participant** - we have had residents come in, they have had dementia and it's very early stages,

55 to the point where if you didn't know them, you wouldn't know that if you had just met them

56 for the first time, and when you, to the point where if you didn't' you would have no clue it's

57 only after you have been told, every now and then you'll be like, oh yeah that's the dementia.

58 **Researcher** - ah so you have a lot of experience with the dementia, haven't you. So with that
59 in mind, what's your, say you have never met me and you was telling someone new, what
60 you're understanding of dementia?

61 **Participant** - ok, erm... I think the best way to describe it, they showed us a picture of dementia,
62 you might have seen it, and it was like a healthy brain, and a brain
63 with dementia, its sounds a nasty way of putting it but, it looks like
64 lights are going off in the, you know the brain. Yeah, like little bits of
65 the brain are shutting down, like one bit might affect memory, one bit
66 might affect motor skills, and cognition, and that how I understand,
67 like things are changing and they don't know why there are changing.
68

Participant tries to capture their understanding of dementia by using visual representations and examples. Uses metaphors to explain the progression of the disease. Appreciates the changes and confusion with things changing without full understanding

Has 11 year experience with dementia residents. Very family with Dementia. Understands how dementia is a difficult to see sometimes. Perhaps indicating how certain things indicate that an individual is living with Dementia.

Awareness of changes.

69 **Researcher** - And how's, obviously because they have dementia, how's that affect your typical
70 working day, does it, is it any different, are there any things you have to consider?

71 **Participant** - erm, not, yeah, but I think, I hope, I'm not over estimating myself here, but I
72 think I've got it under control now, its things like, people talk to people with dementia like
73 there little children, you know so its things like, talking to people with dementia like I'm talking
74 to you, even if they don't understand as clearly, try and you know, give
75 them the respect they deserve, this is still an adult, you know this
76 might be someone who's like 50 years older than me, I shouldn't be
77 talking down to them like there seven.

Mutual respect between care-giver and resident appear to be a factor which is important in a care-giving relationship. Some hesitation in answering this question. Talks about a sense of control. Perhaps to do with the dementia resident and control over the working day. Explains how people can talk to dementia residents like they are children. Thinks it's important to speak to them humanly. Understands how its an easy thing to do- reconsidering the individual and their position towards the carer, Making a comparison.

78 **Researcher** - Yeah, so... What about you're routine? Obviously in
79 your work place you have your own routine... Meeting tasks...

80 **Participant** - yeah erm, yeah the routines one of the most frustrating
 81 things about it, because a lot of the time the routine takes away from
 82 the individuality of the people, and spending time with them, you fall
 83 into a trap, were its just, get people up, get people fed, get people sat
 84 down, get them ready for their next meal, and there me with them, you
 85 fall into a trap. To people with dementia like and having a chat with
 86 them, or you know, just nattering with them really, which sometimes
 87 you get to do, maybe at meals times and that, but a lot of the time, you
 88 know on a busy and its gets forgotten about, it's probably the most
 89 important part of the day, but it's the bit that gets put to the back.

Expresses frustration with the routine.
 Explain as though- like a 'to-do' list, so to speak.
 Five minutes could make a big difference- go a long way. Importance of small talk.
 Explains how this is not always happening due to routines- but understands that actually this is very important. These little conversations can be forgot.
 Sense of frustration

Sense of embarrassment, but truth in what the participant was doing.

Feels that perhaps the residents are affected by these factors sometimes. Friendships - little things mean a lot. Spending time with the residents appears to be of importance to the participant
 Metaphor of the routine being a trap.
 Restricting the relationship. Perhaps hindering the opportunities for developing relationships.

Talking is important

90 **Researcher** - What about stress?

91 **Participant** - Erm. Yeah

92 **Researcher** - do you find it stressful?

93 **Participant** - Yeah, a lot of the time yeah, but I don't think that
 94 sometimes you get to do, maybe at meal I think that's more to do with
 95 the organization not providing enough resources, enough staff, enough
 96 time.. Yeah it's do with the organization not providing enough
 97 resources, I have lost my temper, not aggressively, I have snapped at
 98 people before now, I've got frustrated..

Agrees that it is stressful. But understands this is not because of the residents- its external factors. Express how stress can get the better of you sometimes

Organisational strains - affecting opportunities for relationships.

Reflecting on own feelings regarding - the outcomes and strain on staff. Linked to the frustration of organisational resources.

99 **Researcher**- yeah yeah.

100 **Participant** - erm Like anybody else, erm, but it's never really because of the person it's
 101 because, it's always some things that, unfortunately some people pay the price for.

102 **Researcher** - Yeah so- what about some of your experiences positive or negative working with
 103 - well we have just talked about that- but any particular examples?

104 **Participant** - erm, just friendships really, it's little daft stuff, like A little means a lot. Small acts of kindness

105 unfortunately some have passed away now, but times when like, you just have half an hour

106 sitting watching boxing with a guy, like I couldn't care less about boxing or football really, but

107 just sitting having half an hour watching it with the residents, there the Allowing time to connect = job satisfaction

108 little bits that I remember. This shows the amount of residents which come and go over the years.

109 **Researcher** - Yeah

110 **Participant** – There are little bits that I remember. I'm struggling to remember them all in my

111 head, but but it's the little moments you remember the most.

112 **Researcher** - aww that's nice.

113 **Researcher** – like when you come into like, a particularly busy shift, how do you feel when

114 you have to deal with these particular challenges?

115 **Participant** - Erm, as long as you have a good team around you, I

116 don't mind it in the slightest you can have two or three people working

117 together to look after these people, or you can have three people

118 working separately, technically all in the same place. And so, as long

119 as you're all on the same page and your all working towards the same

120 goal, you weigh it between you, its fine, it working towards the same goal, separately,

121 technically all in the same place, it needs people, you need a good

122 team around you. Teamwork.

123 **Researcher** - So are there times where you have felt like, say your particularly stressed at work

124 has that like ever affected you outside of work? Importance of staff having mutual understanding with one another.

Effective eco system.

125 **Participant** - Yeah it did, not even isolated moments, a couple of
 126 years ago, I was really unhappy, I noticed, I don't know how relevant
 127 this will be to you but, I went from going to bed at night, lying there
 128 relaxed, and then completely chilled out, to lying there being stressful,
 129 on edge, and I realized sometimes probably at that point it started creeping over into the rest of
 130 my life, which id always been quite good at separating until then.

Participant admits feeling unhappy as a result of work factors, during his time as a health care professional, there have been time where the participant has come home with worries. Realises that you should be able to separate the idea of work and home life. Shows how emotional the job can be on occasions

131 **Researcher** - yeah

Talks about how work can affect you outside of work. Moments play on the participant's conscience. Talks about stress when at home. How sometimes you cannot always separate work from home life.

132 **Researcher**-So what do you think about maintaining good relationships and what does this
 133 mean to you?

134 **Participant** - Erm yeah I think it about maintaining good relationships
 135 and what don't do that job if you can't, maintain relationships.

Quite a bold comment regarding the idea that you shouldn't be in the job if you cannot maintain relationships

136 **Researcher** - yeah

137 **Participant** - It's trying to break down the idea of you being the carer and them being the
 138 residents, your just two adults, or however many adults, working
 139 together. Yeah. Have a friendship with them as much as anything.

Idea of having a friendship with the residents coming through here. The idea of the health care professional in partnership with the resident, working together

140 **Researcher** - Obviously every relationships going to be different but
 141 how would you describe your own relationship with residents.

The participant recognising their own qualities and feels that maintaining relationships is the aspect of the job they are the best at. Feels that they have a good relationship with the residents they care for

142 **Participants** - I think if every relationships going to be do the job I'm
 143 best at.

144 **Researcher** - Do you think this relationships that you have do you think it affects your typical
 145 day?

146 **Participant** - Erm, not really, it affects, I've had to catch myself, kind of contradicting what I
 147 was saying about talking as normally as you can to people, but I have in the past found myself

148 talking to non-dementia residents, as if they have dementia, I'm that
149 used to doing it and I've trip myself up, and had to like give myself a
150 slap on the wrists and like stop patronizing them.

Expresses how there is a particular way to communicate with dementia residents – uses the work patronizing – perhaps indicating the participants sometimes has to talk to the residents as though they are children?

151 **Researcher.** - Yeah, let me rephrase this, you say you've got quite a good relationship with the
152 residents, do you think this benefits your, in your erm, in the way that the shift runs, do you get
153 what I mean?

154 **Participant** - yeah if you spend all day looking after people you didn't
155 care about, you wouldn't do it to that same standard.

Interesting point here – states how if the participant didn't really care for the residents, their standard of care wouldn't be the same as someone they had a better relationship with. Interesting in that it shows the importance of having a good relationship initially

156 **Researcher-** do you...sorry. Do u think that erm what's the word, obviously you have got the
157 relationship, do u think, cos you have got that relationship, do you think the communication
158 you have with residents is better?

159 **Participant** - yeah yeah I think it think if you have got the relationship, do different to learning
160 anything else's, you learn to be compassionate to people, treat them with the amount of respect.

161 **Researcher-** can you talk to me about a time when your relationship with a resident has been
162 positively or negatively impacted because of a certain circumstances out of your control as a
163 care-giver?

164 **Participant-** erm yeah I don't know if this is actually relevant or not, I used to look after a man
165 who, well he was nice to me, we could chat and that, but he could be really nasty to some of
166 the other people who we looked after, and it was people smaller than him, so it was always like
167 you know little ladies, and him being consistently nasty to them, it gets to the point where you
168 start getting annoyed at him, and again this is a matter of dementia and it's not really his fault,
169 but his relationship with them, the way he was treating them, then affected your relationship
170 with him, so it's to the point where the standard of care he was receiving off you suffers, so
171 erm, I can't think of anything outside of the people themselves.

172 **Researchers** - what about families?

173 **Participant** - yeah families I was just going to say that, erm but, not

174 really though, no I feel like, we get the family, we have had family

175 members that have been unpleasant and that, but I've never blamed the

176 resident for that, you know when I think about them, the resident, its

177 two different people, I wouldn't judge you based on your brother or

178 your sister, I wouldn't judge a resident based on their son or daughter.

179 **Researcher**- Have you got any examples of any experiences where you've felt, you know what

180 I've done a good job today, or?

181 **Participant** - its little bits like, if you go in and you hear somebody

182 telling their daughter yeah he's nice him, its them little bits that, I

183 always try work to a decent standard, so it's never oh I was particularly good at, you know,

184 helping somebody, you know it's the overall picture , when you get a clue that they do

185 appreciate it that's the bits that you take away, I mean there is a down

186 sides to that, which is that the residents are able to tell you that or the

187 families the ones with the least serve dementia, so as the illness progresses it's harder, so u

188 know is this person happy, and I doing the right things for this person, so they can't always tell

189 you that, that's like the flip side of that coin.

190 **Researcher** - yeah. Sorry, so in your own words, say you had never met and I was a new starter

191 or something, how would you describe you ideal relationship with a dementia patient? What

192 sort of images come to mind?

193 **Participant** - erm it's what we were saying before, treat everyone on an equal level to you, it

194 not your up here and there down there, you're in charge or anything, it's like this, like there

Participant talking about a particular experience. Expresses how his relationship with him has been affected by external factors. Expresses empathy in that the participant understands it's not the residents fault for acting a particular way. Demonstrates the difficulties faced with relationships

Participant has not pre-conceptions of the resident, non-judgmental. Good basis for maintaining relationships

Express how small acts of appreciation mean a lot to the participant

The appreciation comes from the families most of the time as it is difficult for the residents to express that with having severe dementia.

195 shouldn't be a power balance there, it's just supposed to be two
196 people, and if you can get that right, it is possible to get that right, it
197 doesn't matter how severe the dementia is.

Believes equality is important factor to relationships with dementia residents and that is possible regardless of how severe the dementia is. The fact the participant states there shouldn't be a power imbalance, perhaps suggests the participant has seen cases where this has occurred?

198 **Researcher** - How would you describe yourself as a caregiver?

199 **Participant** - I think I'm quite good at it, I mean I have my flaws, I said before I've had times
200 where I've, you know made mistakes and made decisions where I've thought, you know that's
201 not the right thing to do.

202 **Researcher** - but you only human, isn't it.

203 **Participant** - I think that by and large, I do a good job of it, I hope I'm not being too arrogant
204 saying that.

205 **Researcher** - no no not at all. You know when you first started working as a carer, erm what
206 was it like, was it any different to what it's like now?

207 **Participant** - yeah it was miles easier because, this it doesn't really apply to the general set of
208 dementia but where I worked it was a new part of the building, so when I started it was a new
209 part of the building, so when I started it was one resident to three staff, for a couple of weeks,
210 then there was two, so I spending all day with this one person, getting to sit and know them,
211 chat with them, and making their life, you know giving them the highest standard of living that
212 they could get, the second person came in and you spent time to get to
213 know that person.

214 **Researcher** - so you had one person?

215 **Participant** - started with just one resident in the entire place yeah,
216 and then the next one came and then gradually built up to be full.

217 **Researcher** - so I had one carer for every?

Participant talks about what the care home he worked for used to be like when it first opened- explains how relationships with residents were perhaps a lot stronger – as a result of having more time to spend to get to know the resident. Implies how the standard of care was higher as a result of this. Also explains how it was less stressful. Whereas now work seems very task based

218 **Participant** - it was, no there just one single resident in the whole place cos it was brand new,
219 there was nobody living there. so the first person came, had a bit of time, rather than filling it
220 straight away, they staggered it so you got to know them a lot better as a result of that obviously
221 less people meant more time with that person, so the workload wasn't the same, wasn't as
222 stressful, it was just very different, like you spent more time on the personal aspect back then,
223 whereas now it feels more like task based all the time.

224 **Researcher** - I think we've just covered that, you've just answered my next question. (Laughs)
225 the next one was how were your relationships different when you first started to now, what's
226 changed?

227 **Participant** - Well yeah, what we've just covered, but I've been caring now for 10-11 years, I
228 was completely new it then, so how I approach dementia has changed, so

229 **Researcher** - so how did you approach it when. This isn't on there but

230 **Participant** -. This isn't on there but now for 10-11 years, I was
231 completely new in.

232 **Researcher** - so you've learnt that over time?

233 **Participant** - yeah I learnt on the go, the gentle man who mentored
234 me, he's moved on since now, but he was really good at his job so working with him, I think
235 helped me a lot. Erm

236 **Researcher** - erm do you think your personality makes a difference to how to form
237 relationships with these dementia resident?

238 **Participant** - Erm yeah I think everybody personality effects sort of
239 that relationship with anybody, I don't think that resident? job so dementia, some people are
240 good at talking to people, some not so much, some people are good at forming relationships,

Participants explains how his experience and time as a caregiver has changed their understanding of how to communicate and form a relationship with a dementia resident. Expresses how they has no experience of understanding of dementia initially, also understands how they have learnt on the job over the years. Explains how he learnt through observation form someone with longer experience than him.

Believes personality affects relationships as a whole

241 some others find it difficult, again it goes back to, this isn't somebody with dementia, it's
242 somebody, just another person in your life.

243 **Researcher** - Erm obviously you probably, you've heard of person centred care, so have you
244 got any opinions on that?

245 **Participant** - I think it's a great idea, but a lot of it doesn't always happen, there only ever so
246 much time in a shift and only certain amount of time to do certain tasks, like you can't not get
247 everybody up, you can't not feed everybody, those things have to be done, then unfortunately
248 person centred care sometimes falls by the waist side, it shouldn't do, we don't want it to, but
249 when you have only got so much time in a day, you got other decisions to what you can do and
250 what you can't, like you can still use person centered care within the things you have to do,
251 like we used to have a guy who always used to like wearing a suite and a tie every day, so we
252 let him. but erm, you know, you got people who always know what they want to eat or drink,
253 so you do use some person centered care in that sense, you don't just say here's x amounts of
254 the same meal, here have one each, but then things like, again, I mean, one on one time, that a
255 lot of the time doesn't happen, where in that sense the idea of person
256 centered care gets lost.

257 **Researcher** - what do you think of current government policies
258 regarding care for those living with dementia?

259 **Participant** - erm I don't know any, I don't check, I, I, I just trying and just do my bit and
260 there whether the policies change or not. they I can't think, erm it's not a government policy
261 but we used to get told like if, like we used to have resident who would ask about a deceased
262 family member and we used to get told, just tell them they're dead, and then they would get
263 upset, then they would ask again the next day, we just told them again and again, it got to the

Believe PCC is a good idea, however practicalities of if sometimes don't occur. Participant give examples of this. Expresses how you can use pcc in small aspects of care and gives examples, expresses how it should be in place all the time however circumstances stop it

264 point where you thought no I'm not keep telling them that, there's bits , things you can disagree
265 with..

Has a limited understanding of government policies. Gives an example of something similar, more related to the Idea to the debate of therapeutic lies in care

266 **Researcher** - What about erm, mental capacity act?

267 **Participant** - Erm

268 **Researcher** - any opinions on that?

269 **Participant** - Erm

270 **Researcher** - in terms of like, let me put it into context,

271 **Participant** - in terms of letting them?

272 **Researcher** - erm... Like decisions being made by families

273 **Participant** - yeah, well it depends what the decision is really, like we have got a resident
274 who's could happily make the decision for themselves to go out the door and walk into the
275 street, but then they would end up getting hurt, so you have got to have limits.

276 **Researcher**- This is like a future question really, what do you think care practices will be like
277 in another 5 or 10 years from now?

278 **Participant** - I don't like a future question really, what do you think care practices will be like
279 in will.

Participant doesn't think much will change in regards to care practices but believes they should

280 **Researcher** - what about relationships with care-giver and the
281 residents?

282 **Participant** - erm yeah they will vary from place to place, it's a processing thing, if somebody
283 starts work tomorrow, it will be different to how I do my job now, but by and large,
284 relationships will hopefully be similar and to a decent standard.

Believes every care giver is different. Believes talking is the key to natural relationships. Participant believes that relationships will be similar and hopes that there at a decent standard.

285 **Researcher** - this isn't on here either but do you think there's any how to make relationships
286 or do you think it's just something that should happen naturally?

287 **Participant** - erm people have to talk to people, I had a chap, a guy once who came in who
288 was on a course, they guy came in with his wife, they just came in and basically sat down and
289 said to us , and put things into perspective as a husband, his wife no longer recognises him, and
290 been suffering with dementia for years, so it's just, you're not going to sit down and read a
291 book and say I can do that course, it just about talking really.

292 **Researcher** - and that's everything, thank you for your time.

1 **Interview 2**

2 **Researcher** - can I just confirm that you have read the consent form, information sheet, read
3 everything and are happy with everything? Ready to continue?

4 **Participant**- ready to continue.

5 **Researcher** and participant- laughs

6 **Researcher** - ok, so when I'm doing, imagine that you don't know me. That I don't know
7 anything about dementia or the job, like I'm a total stranger coming in asking you about your
8 experience.

9 **Researcher** and participant- yeah.

10 **Participant** - got it total stranger.

11 **Researcher**- so if we start with, erm, what a typical day is like for you, it can be a morning or
12 evening shift.

13 **Participant**- at work?

14 **Researcher**- yeah.

15 **Participant** - Ok - so I come on to shift, take hand over from the night staff, on the morning
16 shift , then get everybody ready, erm each person at a time, delegate a different person to
17 different members of staff, erm, some with be for a bath or shower, some for a wash, and
18 getting dressed. Then from that we get everybody seated in the dining area ready for
19 breakfast. Feed people who can't feed themselves, some can, then following breakfast you
20 make sure everybody's comfortable in the lounge, or if somewhat to go back to their rooms.
21 Then we make all the beds, make sure all the rooms are tidy, then we do mid-morning drinks,
22 everybody has a drink, erm and then you start taking everyone to the toilet before lunch time,
23 that can take quite a while depending on how many people need to go, and the you have

- 24 dinner, same as breakfast, then after dinner you make sure everyone's comfortable, the you
- 25 do your writing up, writing your notes and handover sheet, how
- 26 everyone is, how everyone's been.
- 27 **Researcher**- yeah - what about a late shift?
- 28 **Participant**- so on a late shift you put all the laundry away that's
- 29 come back, the laundry put all that away, make sure everybody's got
- 30 a fresh flannel, towel for the next morning, erm then.. you do drinks, midafternoon drinks, so
- 31 that's that. Then you start getting everybody ready for dinner, take them to the toilet if
- 32 they need to go, that can take quite a while, and then have tea,
- 33 feeding and then after tea, make sure everyone has settled, make sure
- 34 everyone has a hot drink, settle them before bed. Then some of them will go to bed earlier
- 35 than the others, erm starting to fall asleep in the lounge, then go early. Then from around
- 36 half...from around 7 to 9 that's when everyone gradually starts putting people in bed,
- 37 depending on when they want to go.
- 38 **Researcher**- would you say that runs smoothly every time or?
- 39 **Participant**- not every time.
- 40 **Researcher** - what's that like?
- 41 **Participant**- Erm, that depends on the residents you have at the time, when you have quite
- 42 calm, erm, what's the word, erm if you have, if you have residents that aren't any trouble,
- 43 **Researcher** and participant - yeah
- 44 **Participant**-Then, then it's fine, but like if you have, but if you get the occasional one who
- 45 can get very agitated quite easily, a lot of dementia, erm a lot of people with dementia tend to

Participant is explaining the routine of the working day. Both morning and evening shift. Participant refers to working day in a list format.

Some elements of person centred care in here. Having choice of when to go to bed.

Appears to be a lot of preparations being made here.

List like - routine.
Task based.

Explaining the level of demands of the residents depending on the severity of the dementia.

Individuality of the residents.

46 turn a bit when the sun goes down, in darkness. Erm sun down syndrome can sometimes
47 cause chaos

48 , erm I think I t tends to run smoothly most of the time, it's usually
49 one or two people that, if one thing happens, it kinda starts, setting
50 you back a lot, and you might not get as much done as you wanted to by 9 o clock, but if that
51 happens it happens , you just kinda deal with it.

Explains how things going wrong as being sort of like a chain reaction.

52 **Researcher**- obviously you work on a dementia unit, but what's
53 your, to you personally what's your typical understanding of
54 dementia?

Expresses how every person is different. The impact of dementia affects each person differently.
Shows and understanding that how the individual behaves is not them its a result of the dementia

Again Individuality.

55 **Participant** - Erm my understanding of dementia, erm I think I understand that it varies in
56 each person with dementia, it doesn't affect the other person the
57 same at all. Erm it can affect people very negatively, it can bring out
58 , it can change the personality completely, could have been a nice, happy , easy going
59 person, it can change them in like an aggressive person, no fault of their own, it's just what
60 it's done to them. Erm it... it's a hard question.

The perception of the changes dementia has on someone are viewed negatively by this participant.

61 **Researcher**- what about like, erm

62 **Participant** - you understand that nothing, you have to understand that most things they do
63 they don't know there doing it.

64 **Researcher**- yeah

Again the theme of 'how to react' crops up.

65 **Participant**- it's not them, you can't take anything personally, they're not attacking the
66 person, it's just they don't know that there doing it most of the time, if they come across like,
67 lucid, but still don't understand the action that there doing,

68 **Researcher**- How would you say like your understanding of d, like

69 your experiences, how do you think that affects other people, like, do you think you

70 understanding of dementia is different to other people's, if you know what I mean?

71 **Participant** - with who I work with? Erm, I think it can be, I think

72 how you react to people with dementia and how you cope with

73 them, I definitely think the longer you have done it, the better you

74 are with it, like you'll see erm, people who have worked with it for

75 quite a long time can handle situations a lot better, it doesn't seem to

76 stress them out at all, whereas people , new members of staff who never crossed dementia

77 before and they don't understand it as much , sometimes don't understand what they're

78 doing, are not very calm when the handle things, and can panic.

79 **Researcher**- can you erm, have you got any experiences positive or negative about working

80 with residents with dementia?

81 **Participant**-mm loads

82 **Researcher** -anything that stands out to you the most, you don't have to name any names.

83 **Participant** - Positive or negative, positive as a whole, a lot of people with dementia they,

84 when there nice there really nice, there the sweetest people in the world, and it makes your

85 shift sort of, and then probably bad ones I've had, there not necessarily, the ones that are

86 aggressive , it's more the demanding ones, the ones that don't settles, that's probably what's

87 the most challenging, the ones that won't sit down or won't stop shouting, just because there

88 not settled, I think there the most difficult, to kinda cope with.

89 **Researcher** - how do you feel when you have to cope with these

90 particular challenges that you have got to deal with?

Elements of the reflective triad here.

Takes time to understand and cope with certain behaviours/ associated with dementia.

Coping with demands comes down to experience. Explains the difficulties new starters face.

Quite an unsettling experience at first.

Participant shows a great deal of respect for the residents Kept original speech – colloquialisms

Being in the unfamiliar situations can cause stress.

The experience of working with dementia residents appears to be positive as a whole.

Speaks about how it can be difficult to cope with sometimes. Expresses how time has allowed her to deal with the challenges more easily. Stresses an important of getting to know the resident.
Tells us about how you automatically get to know the resident on a personal level, and this can be difficultly to come to terms with in the event of a death.

91 **Participant** - Erm, I don't, I don't think about it very much
92 anymore, I think, when I , when I first, I've been doing it over four
93 years now, and in the very beginning, I panicked sometimes, cos especially if there's only a
94 couple of you on shift, I think it can be quite daunting, if you haven't been in the situation
95 before, and you don't know how to handle it, but I think as the
96 years have gone on, erm I haven't found anything that has surprised
97 me recently, so a lot of the situations seem to be reoccurring or you see it before so you know
98 how to handle it, and you know the person as well, you get to know them, so you kind of get
99 to know what calms them down, what agitates them.

100 **Researcher** - so as a health care professional do you think there are often times when
101 particular stressors at work has affected you outside of work?

102 **Participant** - Erm yeah, I think, if you get quite close to a resident, or ones been there for a
103 long time, , you have kind of seen them from, the start of the dementia to the end and you
104 have seen them progress, and then I think when you lose that
105 person, I think it can affect you, you try and not let it, but when
106 you have known them a long time it obviously does, it's something
107 you think about when you come home from your shift.

108 **Researcher** - so what do you think about maintaining good
109 relationships with residents in the home, does this have any meaning to you?

110 **Participant** - Erm yeah, yeah definitely, I've though they don't remember, from day to day,
111 they might have me you a hundred times, but they don't know that it's you, there's little
112 things you can do, that they really appreciate.

113 **Researcher** - what sort of things?

114 **Participant** - Erm so there's one resident who erm loves having a shave in the morning, and
115 if he doesn't have a shave, he gets quite annoyed by it, so when he does he's really grateful, I
116 think that's, they won't remember you in an hours' time, but when there really grateful, it
117 makes you feel good, make you feel like you're doing, makes you feel like you got a better
118 bond with them.

119 **Researcher** - So obviously like every relationships going to be different as you said, but how
120 would you describe your overall relationship with the residents?

121 **Participant** - I think it's quite good, erm I've never had any
122 problems with me specifically, you have the occasional ones shouting at you sometimes, but
123 it's not directed at you, it can be directed at anybody, I've never had a problem with a resident
124 directed at me over something I have done, luckily.

| |
|---|
| Understands everyone is different. Individuality |
|---|

125 **Researcher** - any like when your communicating with a residents with dementia, any
126 different strategies do you use, you know like, I don't know how to work it, like me and you
127 are talking right now, but obviously cos of..

128 **Participant** - so you mean like depending on the individual?

129 **Participant**- Erm yeah yeah, I think it completely varies, so, for example, you can have one
130 resident who gets very agitated, and they can quite easily calmed down by comfort, holding
131 their hand, erm little things like that, really calms them down, we had resident who used to
132 agitated all the time, and they only way to calm her down was to stroke her hair for about ten
133 minutes and she calmed down. Whereas we have another resident who doesn't like physical
134 contact, of any kind and it just makes her worse makes her more agitated, angrier. so that's
135 harder , because you have to find other ways , when they can't communicate, you kind of
136 haven't got the communication aspect very well, there not understanding what you're saying
137 and you also can't comfort them cos they don't like that.

138 **Researcher**- yeah

139 **Participant** - so yeah...

140 **Participant** - erm so the strategies depend on the person.

141 **Researcher** - can you talk about any particular times you thought your relationship with a

142 resident has been positively or negative impacted by circumstances outside of your control as

143 a caregiver?

144 **Participant** - say that again

145 **Researcher** - that's a bit long that one want it, sorry.

146 **Participant** - it's alright

147 **Researcher** - are there any particular times where you feel your relationships been affected

148 with that person because of something that's nothing to do with you and out of your control?

149 **Participant** - do you mean like something else, unrelated to you, was to agitate a resident,

150 but they would take it out on you, yeah yeah daily, that can happen a lot, say if there, say if

151 you work, say if another member of staff was getting someone ready in the morning, and they

152 don't like getting up in the morning, and not a morning person and very annoyed at that

153 member of staff, but they see you and see the uniform, they're going to take it out on you,

154 they don't know who they're shouting at , it's not your fault, it

155 nothing that can really help it. Also relatives, sometimes relatives

156 can agitate, family members, they don't always want them there, you

157 know, sometimes it can confuse them more, when they leave, they

158 don't always understand why there leaving, erm which can make them feel trapped, like there

159 trapped there, then once they have left, and there in a terrible mood, it can, they can talk it out

160 on you, and there's nothing that can be done about it.

Having to think outside the box and find ways to connect when communication is not possible. Understands that behavior like shouting and aggression is not a result of them. Talks about how residents can be confused with relationships especially when family members come and go regularly.

161 **Researcher**- Have you got any experiences that you found to be satisfying, in terms of the
162 way you give care as a care giver, does that make sense?

163 **Participant**- Sort of - say that again

164 **Researcher** - any times where you have felt like, I've done so- , like you've made a
165 difference sort of thing? Do you know what I mean?

166 **Participant** - ooo yeah, erm, there's little things that you do, erm
167 , you could, erm there a resident who doesn't really like getting

Little things mean a lot potential theme.
Again talks about how small acts make a big difference.
Understands how the relationship can be clouded to the resident. But a familiar face is comforting for the resident.

168 up, and erm , to , when she hasn't got ready in the morning, she's in a very bad mood, and
169 once you encourage her and eventually persuade to have a wash or a shower or put on a bit
170 of makeup like she does, she in a ten times better mood, and she's so grateful and thankful ,
171 erm and she like can't believe how much better I feel now. It's like like that's satisfying
172 because you feel like you persuaded her to do it and she will have a better day now for it.

173 **Researcher** - ok so say you don't know me and I'm totally new and I'm about to start
174 working with you or something, what would you say is like the ideal relationship between
175 you as a care-giver and resident, what sort of words come to mind?

176 **Participant** - erm well, obviously professionalism always important, but I think it's more

177 difficult with dementia, especially with erm, my age I think a lot of
178 the time some of them see you as their grandchild, or a child, erm
179 because they don't know where you are, I've had it where I've been
180 treated as grandchild, so I think , I think the relationship can get a
181 bit blurry to them, they don't really know who you are, I think it's

Shows the complexity and confusion dementia can cause – especially to care-givers. Relationships in dementia can often be misunderstood, due to the symptoms associated. Kind of highlights the importance of being that familiar face, as a way of respecting that we understand the confusion they must be experiencing, by allowing them to perceive the relationship as this. Giving peace of mind.

182 nice to be a familiar face, you know, a reassuring face, I think that's

Potential themes – A familiar friend

183 the best thing that they can get out of it, it would be nice if they recognised you, even if they
184 didn't really know who you were, they kind of thought, I know that there a nice person, I

185 remember them, I don't know what I remember them from, but I recognise them from that
186 they was nice to me, I think that's best.

187 **Researcher** - how would you describe yourself as a care-giver?

All three interviews seem to enjoy their jobs
– and believe they are good care-givers.

188 **Participant** - ooo erm, I like to think I'm good, I'm kind, erm I have personal experience of
189 dementia before I started working there.

190 **Researcher**- would you be ok talking about that or?

191 **Participant** - yeah my nana was a resident on the unit that I worked, for four and half years,
192 erm the initial , I saw from the initial diagnosis, I saw erm, the initials diagnoses, from the

193 end stage dementia, I saw the whole process, I think helped in
194 understanding it, from a very young age, so I do like to think I have
195 a good understanding of dementia, I can like, compared to people
196 who have never been exposed to it before, I've dealt with certain
197 aspects of behaviour from that, I knew from very young, I
198 understood that not a lot that was said, was not here talking it was
199 the disease, but I think I was quite prepared when I came to the job.

Shows understanding and appreciates their point of view of the relationship, by accepting that as the relationship being that way.
Has first person experience of dementia as family member experienced.
Every day is different.
Over time you being to recognise different personality traits making situations easier to handle.
Understands how initially the job can be quite stressful and make you panic.
There is more to the job and completing tasks, required work on an emotional level of understanding.

200 **Researcher** - erm when you first, we just spoke about that, but when you first started was it a
201 lot different than how you are now in the way you work?

202 **Participant** - yeah , erm , on starting any new job, is quite daunting, but I think it is
203 especially scary job to come into, cos there's coming into a job and not knowing what to
204 expect, but this is job where you don't know what to expect every day, it can change every
205 day, you can have a really good shift and a really bad shift, cos you can't predict behaviour,
206 so there's constant challenges with that, erm I think over time you get used to certain
207 personality traits, erm you understand them more, you understand them as an individual, so
208 over time there isn't that much that shocks you, most situations you have been in before, so

209 you feel like you can handle it, obviously you get the odd one where don't and its completely
210 new, but I think a lot of the time, over the years of being there, you just kinda get used to it.

211 **Researcher** - so you think it's quite,

212 **Participant** - you feel more prepared yeah, I think when you first start you get you get very
213 nervous, but over time you don't.

214 **Researcher** - so you think it's quite important to get to know them, you think that's quite an
215 important process of it?

216 **Participant** - yeah I don't think it's a very task orientated job, you know you come in you do
217 your task and you go home, I think there's a great importance on, getting to know person as
218 an individual, because each individual has certain things that can trigger the bad side, and
219 ways to calm them down, one technique doesn't necessary work for every single resident, you
220 have to get used to that.

221 **Researcher** - so obviously everything you was talking about, what do you think, have you
222 got any opinions on person-centred care?

223 **Participant**- yeah it was in my assignment that I've just done, erm
224 so, person-centred care is about getting the individual involved in
225 their own care, encouraging them to make their own decisions such
226 things like that, I think it's quite difficult to achieve in a sense,
227 obviously not with all of them but, I think it's nice when someone
228 comes onto the unit, I think it's quite nice to keep the independence,
229 and make decisions for themselves, if they can, if they want to get
230 up a specific time, or they don't want to eat at a specific time, or erm, if they don't want a
231 shower, I think its fine, it's good to keep that independence, and making decisions, I think it

Encouraging independence appears to be important factor of PCC and decision making.
Time coming up as a factor which causes barriers to good quality care. In balance of attention can cause complications on the unit.
Policies hard to keep up with. not being communicated to the staff.
Understands the prevalence of dementia is on the rise, which comes with questions about having enough staff and facilities to accommodate.
Mentions the difference in pay from uk and abroad.
Believes the relationships with improve - as awareness increases, so will understanding.

232 triggers, it keeps a bit of their own personality there, so I think
233 if you can, encourage person centred care, they do still have a
234 little capacity there.

Understands the concept and meaning behind PCC yet understands they're barriers and explains these in the context of the working day.

235 **Researcher** - that's good, what do you think the main issues are that effect relationships
236 between care-givers and residents?

237 **Participants** - erm I think yeah, if you the units full and a lot of the residents are very
238 challenging, then I think that can cause issues cos you haven't got as much time, erm
239 individual one to one time, I think some, when that attentions not there, they find other ways
240 to get attention, you know they get bored sat there, they obviously want to do something, but
241 that can cause problems, and bit much to handle, erm.

242 **Researcher** - erm what was you assignment on, I know it's not on here?

243 **Participant** - the one I've just done, erm I had to pick a patient that I looked after and talk
244 about an aspect of the care and why it was challenging, so I picked the cardiac arrest I did,
245 and talked about the challenged I faced from the first time student nurse. So I talk about how
246 I thought it was difficult to achieve person-centred care. Because obviously I couldn't make
247 the decisions for them so I had to look to the family, erm I talked about leadership involved
248 team work, how it can lead to better outcomes.

249 **Researcher** - it relates quite well really,

250 **Researcher** - what do you think about government policies regarding care for those living
251 with dementia.

252 **Participant** - I know that government policies change all the time in regards to care, Does
253 policies change all the time in dementia, there constantly changing and are quite hard to keep
254 up with.

255 **Researcher** - do you think that's an issue for the residents?

256 **Participant** - I think it's an issue for the staff, cos obviously say if you find out about policy,
 257 and then it chances and then you never find out about it, it's not like you your constantly told
 258 when its updated, the way to find out is if you go any check, which a lot of people don't do.

259 **Researcher** - What do you think care practices will be like in another 5 or 10 years from
 260 now, especially for residents living dementia?

261 **Participant** - Honestly, I think, I don't think erm there will be enough places to live, I think
 262 the prevalence of dementia is increasing rapidly, especially over the last ten years, erm so I
 263 think, more it rises the more places are needed to house people who can't look after their
 264 selves in their own environment, I don't think there will be enough staff, no I think a lot of
 265 health care professionals, tend to go abroad these days, I mean the moneys better over there,
 266 lives better over there, so there isn't as many nurses and health care assistants as there was.

267 **Researcher** - what about relationships with care-givers and residents over the next five
 268 years? Do you think what you said before will impart that?

269 **Participant** - I think they will improve relationships, because I think, ten years ago, there
 270 wasn't much information about dementia, it seems to come to light so much over the past few
 271 years, there is a lot more charities and awareness about it, I think people understand it a lot
 272 more, things like Alzheimer's Society and Dementia UK, they do a lot, they try raise
 273 awareness of it, I think because of that, because over years more understanding of it people
 274 will be more aware of it, people will feel more prepared going into the job, and improve
 275 relationships.

| |
|--|
| Shows positivity towards the idea of relationships improving. Optimistic |
|--|

1 **Interview 3**

2 **Researcher** - so if you imagine you have never met me and I'm asking these questions as an
3 outsider and that I don't know anything about dementia. Yeah ok? What's a typical working
4 day like for you?

5 **Participant** - Busy, just general care, it is very busy, just trying to convince them, were
6 going to have a good day. getting them in the right mood, the right frame of mind, with the
7 dementia if you do get them in that frame of mind and that good mood, then it will last, see to
8 their needs, explain to them what you're doing, just because they have got dementia doesn't
9 mean they don't know what you're doing, cos they do, erm, giving them a choice of food, you
10 know they do know what they like and what they don't, if they can't say it they will point.

11 **Researcher** - what about night shifts?

12 **Participants** - Well there all in quite good patterns, good sleeping patterns now, but it's like
13 when we get a new, I see to the older ones, and by older I don't mean older as in person, older
14 as in the length of time they have been here, and then work with the new one, try and get
15 them in a routine, it can take weeks sometimes, but I've been quite lucky, and its took 2 week
16 maximum, so it's been quite good.

17 **Researcher** - what's the routine like the working routine like working here?

18 **Participants** - Yeah it's pretty good.

19 **Researcher** - erm I know we work together but if you can imagine that you don't know me,
20 can you describe what types of residents you worked with in your time here?

21 **Participant** - in my time here what whole residents?

22 **Researcher** - Yeah

23 **Participant** - yeah, cos I've not just worked on here you know with the dementia, I've
24 worked on the nursing side, with strokes and cancer patients, end of life mainly, it's quite

25 hard, but it's quite touching as well really cos you get attached to them. erm it's pretty sad,
26 whereas with the dementia it's a different atmosphere, totally different.

27 **Researcher** - what do you mean?

28 **Participant** - like over there, over on the other side it nursing it's like working in a hospital,
29 the majority might stay in bed, if there not in bed there in wheel chairs, wheelchair bound,
30 very little walk, erm they have different needs you know, it's like , fluid every house,
31 whereas here, we give them drinks they do it their self, you know and you do know when
32 these want a drink, over there, it's like, there having it, you know, their maybe on end of life,
33 or its routine thing with them like the cancer patients, they you know, the injections, this and
34 that, it's quite hard work on the nursing side but you have got a lot more staff as well.

35 Whereas, dementia residential, we only have the 12 residents, whereas even three staff it can
36 be hard work, because they do take up a lot of time.

37 **Researcher**- and is that because of the dementia or?

38 **Participant** - yeah yeah, course it is the dementia, like a said before, it's in the frame of mind
39 you get them in and it goes of the person getting them ready that morning, it's about
40 explaining to them what you're doing, don't just go in and wash and dress them,
41 you know, tell them what they're doing, give them the flannel you know they might wash
42 there selves, you know and just encourage them but I do think it think it does go off how they
43 have got up in the morning, what mood there going be in for the rest of the day.

44 **Researcher** - so with this in mind, what your own personal understanding of dementia?
45 How's this affect your typical day?

46 **Participant**- my own personal, erm, understanding it really, you need to understand the
47 dementia to know how they are, erm my father in law had dementia, so I sort of like new how
48 to look after him through looking after these here, erm , and understanding it, it takes time,
49 and when you do understand it, it's really sad, it's a sad illness, you know they don't

50 understand a lot of them, they don't know what they're doing, they still want to go home,
51 doesn't matter how long they have been here, all they refer to is home, going to doors, like
52 the fire exit door, they want to go out, so they still know that this isn't there real home, you
53 know, and understanding that, it is sad. It's pretty sad really.

54 **Researcher** - so have you got any experiences positive or negative working with dementia
55 residents? Any Examples

56 **Participant** - I love working with them, I think it's amazing. it's good to know a lot about
57 dementia I think, a lot of people don't understand it, you don't know what's going on, in each,
58 in and everyone on is a different individual there all, known of them are the same, erm I'd
59 love to know what they think, I would love to know that, you from what they say, what
60 they're actually thinking in their mind, erm you know one lady we have got, she will talk
61 about something, but she will be doing something with her hands, like she was a machinist or
62 something, and she was nothing of the sort, you know and when she's talking, she's happy,
63 and gets carried away with her talking but you haven't got a clue what she's talking about.
64 You just have to agree with her and she agrees back with you, and it's pretty sad that we can't
65 understand what she's wanting you know and what she's telling us, but whatever it is in her
66 mind, it makes her happy.

67 **Researcher**-yeah

68 **Participant** - Erm ,we used, we did, there used to be a guy here, who used to lick his finger
69 and flick his thumb constantly, and he was counting money, right, but he had remembered
70 that he had worked in a bank, which is quite strange really, he never, he didn't count, but he
71 was doing the actions of like, counting money constantly, you know with the actions of his
72 hands, you know when we found what he did in the past from his family, then we understood
73 him, we knew, it's just finding out about each and every individual, like, what they're doing

74 and what there thinking, you know it's, then we can make their day better by doing things
75 like that can't we?

76 **Researcher** - yeah, erm what about negative experiences?

77 **Participant** - erm, I don't really look at negative, I try not to, I try and look at everything as
78 positive, you know if you're looking at negative, then things aren't ever going to get better
79 for that person, to improve with them, you know if there new here, and we don't seem to be
80 getting far with them, just keep trying and trying and eventually you do, cos it can be hard
81 and it can take the a will to settle in sometimes, and the surroundings, other people that live
82 here, it's , they got to get used to them as well, but hmmm..

83 **Researcher**- Is there anything you find particularly stressful in a working day?

84 **Participant** - yeah not being able to help the when we don't know what they want, or
85 understanding if they're in pain, a lot of them you can tell, you work them out, there was a
86 lady here once, and you could tell she was in pain, she didn't talk. She could answer yes and
87 no, but it was very rare if she did, but you could by her eyes, she used to squint her eyes if
88 she was in pain, and it's trying to understand that if there in pain or want something and we
89 don't know what they want.

90 **Researcher** - erm are there any times you have took these things home with you?

91 **Participant** - All the time, all the time, always thinking about it.

92 **Researcher** - What sort of things, if you have got any? *laughs* sorry.

93 **Participant** - Erm , if their poorly, you know and you go home, and you're thinking about it,
94 I don't think when you working with these kinds of people, your mind doesn't stop for a
95 while, because you're thinking about it all the time, and if they are poorly and you have gone
96 home and your thinking you know, I could have done this or I could have done that, they
97 might have you know improved bit or, you know you are forever thinking, but yeah I take it
98 home quite a lot.

99 **Researcher** - Erm what do you think about maintaining good relationships with residents in
100 the home. What does this mean to you?

101 **Participant** - A lot , I think you need to , cos we are a small unit and we only have 12 it's
102 like a big happy family really, and I think maintaining a relationship with them on a day to
103 day basis you know where they do recognise you, like, we do have one lady who can't really
104 see, and it's the voices with her that she recognises, and I just think, I do think things like that
105 are important ,you know making them happy, playing music with them, dancing with them,
106 like I did today and they have worn me out.

107 **Researcher** - So obviously every relationships different,

108 **Participant** - totally different - yeah yeah

109 **Researcher** - with each resident,

110 **Participant** - they all react in different ways, you know erm, how can I say it like, some of
111 them like to be hugged to feel comfort I think, erm one gentleman shakes your hand, erm one
112 lady if you wave to her she's happy, she knows that you have noticed she's there, I do think
113 things like that are important, to make them feel safe.

114 **Researcher** - how would you describe your overall relationship with the residents?

115 **Participant** - I think its top, I do. *Laughs*

116 **Researcher** - do you think you own personal relationship with these residents do you think
117 that impacts the flow of your shift?

118 **Participant** - Yeah I do yeah, definitely, and I think you know, if there is something going
119 on at home, and I've come to work, I do try to leave it at the door, you know cos it's not fair
120 on the residents, they do know if your upset, and I do think it has an impact on the day, not
121 only for yourself but it impacts on them residents and it's not fair.

122 **Researcher** - can you talk about a time when you felt your relationship with a resident has
123 been positively or negatively impacted by circumstances out of your control as a caregiver?

124 **Participant** - Yeah I could but I don't want to, cos ill cry.

125 **Researcher** - that's fine do you want me to move on?

126 **Participant** - yeah

127 **Researcher** - Can you talk about any experiences which you found satisfying in terms your

128 own care for them?

129 **Participant** - satisfying for me or for them?

130 **Researcher** - you or both?

131 **Participant** - my every day is satisfied, all long as their happy, I'm satisfied every day.

132 **Researcher** - When are you most satisfied?

133 **Participant** - Erm maybe like, this afternoons shift and I'm saying bye to them, and *blank*

134 is saying 'don't leave me' 'don't go' *laughs* Erm *blank* is saying you know 'are you

135 coming back' 'are you coming back' so they do know, that you do go and you do come back,

136 am satisfied when their that happy.

137 **Researcher** - if you could describe what the ideal relationship between a caregiver and a

138 resident what sort of images come to mind?

139 **Participant** - you mean as in the relationship between them?

140 **Researcher** - yeah as like a new started what would you say to them?

141 **Participant** - Just be yourself, you know, at the end of the day your here for them, not, it's

142 not about you, it's not about your family, your here for them, you know you leave your

143 family at the door, your here to improve, you know, make their life better, you know the last

144 years of their life better.

145 **Researcher** - How would you describe yourself as a care-giver?

146 **Participant** - Good. I think so anyway, I enjoy my job, you know, some people come and it

147 is just a job to them, well I don't look at it like that?

148 **Researcher** - do you think it's important that you have to be a sort of certain type of
 149 personality?

150 **Participant** - Yeah I do , yeah , like we do have the odd member of staff, that doesn't really
 151 talk, it's hard for us to get a conversation, I'm not saying that person is it totally ignorant with
 152 the resident, you know there's not a lot there, and it does make a big difference?

153 **Researcher**- so communication?

154 **Participant** - As an example, it's like, there's a gentle man and he thinks he's being ignored,
 155 but not that, it's like their bit shy but, I don't think they know what to say, and trying to
 156 encourage them is hard work?

157 **Researcher** - so what was it like when you first started working with dementia, compared to
 158 now?

159 **Participant** - aww big difference, I've learnt a lot, and I, you know, I wouldn't expect
 160 somebody new to come in and just be like, like I am, like how some of the others are, I
 161 wouldn't expect that, it takes time and then you get it in the end, you know and you just try
 162 and make them feel relax comfortable and safe. Their happy them, and that is what I would
 163 encourage new staff to be like.

164 **Researcher** - sorry have you got enough time?

165 **Participant** - yeah yeah

166 **Researcher** - What are you opinions on person centred care?

167 **Participant** - hmm I don't really know.

168 **Researcher** - you can be as honest as you want?

169 **Participant** - I really don't know.

170 **Researcher** - do you think it's a good idea or?

171 **Participant** - I do think it's a good idea, I think there should be more staff willing to give to
 172 these resident, and you know, it's I don't know.

173 **Researcher** - it's okay - shall I move on. Erm what do you think are the main issues that
174 affect the relationship between a caregiver and resident?

175 **Participant** - Erm the main issues? Communication, more than anything.

176 **Researcher** - So that's a big one to you?

177 **Participant** - it is, to me it is, that's the major I think, trying to understand them, they get
178 frustrated , a lot of them, cos the majority here, they can't string a sentence together, so
179 understanding them, and trying to help them out and finish that sentence for them, helps them
180 out and makes them happy. I do think that's the major issue me, is the communications and
181 then, to then making them feel comfortable and making them feel clean. There is the odd few,
182 you know if they're not clean within themselves, then their day is not right, they don't feel
183 right all day, and you won't change that until they feel comfortable, so you know hygiene a
184 good thing with them.

185 **Researcher** - Erm what do you think of any current government policies for those living with
186 dementia?

187 **Participant** - no comment

188 **Researcher** - is that for any particular reason or?

189 **Participant** - I don't think they are given what they need, you know, trying to think of an
190 example, I don't think people realise how bad dementia is, and how it does affect them and
191 the families, cos it has a major impact on families, and I don't think they are given enough
192 care, I think I they should be given more, you know they say cancer is bad and they'll get like
193 the 24 hour, whatever they want, why not dementia, cos they need it just as much.

194 **Researcher**- that's really interesting that, erm what do you think care practices will be like 5
195 or ten years from now, especially for residents living with dementia?

196 **Participant** - I really don't know but, I hoping, cos their is a lot of, what they call on telly,
197 like documentaries on dementia, its seems to be becoming more popular now, so hopefully it

198 will improve, and there will be a lot more out there for them, you know, things for them to
199 do, and more staff, I don't think the staffing levels are fair at all for dementia, because some
200 of them do take time, working in a place like this, you know there is only 12 residents, but
201 even when there's just three staff on, I don't think it's enough, you need time with them, you
202 know to make them happy, today we made time for them, cos I do think it is important, it's
203 not about just taking them to the toilet and plonking them in a chair and giving them a drink,
204 that's not what they want, that's not what they want, that's not what they are here for.

205 **Researcher**- this is the last one now I promise you.

206 **Participant** - it's alright

207 **Researcher**- what do you think relationships will be like between care-giver and dementia
208 residents in another 5-10 years from now?

209 **Participant** - Hopefully , I'm hoping it has improved, major, I don't think it's that bad, I don't
210 think it's that bad on this unit at all, and maybe it is because they are younger?

211 **Researcher** - is that lack of education or?

212 **Participant** - no it don't think it's about that, I think it's about communication, and how to be
213 with them, how to react with them, you know if they are having a bad day, it's not stepping
214 back from them and leaving them to their own devices, and without being discriminating, it
215 seems to be the younger ones, they don't know how to react with them, and them learning
216 from us.

217 **Researcher** - so its thing over time.

218 **Participant**- yeah I think they need to do a lot more, courses and stuff for dementia for the
219 new carers, you know, I do think they need to a lot more, I went on a few, one was absolutely
220 fantastic, and it, it did teach me a lot, it was brilliant, like the newest staff here, they haven't
221 been sent on these courses, but why, you know and we somebody here sorting all the courses
222 out and stuff you know for them to learn, and it is really annoying.

223 **Researcher** - why do you think that is?

224 **Participant** - I don't really know why that is, I think it's unfair, it seems to be more about the
225 cancer patients and stoke patients, going on this course, doing first aid, and , but what about
226 dementia, it is at the bottom of the pile, and I'm must honestly say, over the last 12 months
227 I've not know any course for the staff to go on for dementia, I mean, I don't think there's any
228 more that myself or the manager or any senior staff to go on, cos we've done the lot, but the
229 staff been here maybe 2 years three years, they might of done one course, they not gonna
230 learn anything of one course.

231 **Researcher** - that's everything thank you!

232 **Participant** - I hope that helped you, thank you very much.

1 **Interview 4**

2 **Researcher** – Is it recording? Yeah actually – I’ll put it nearer to you because you’re speaking.

3 **Participant** – Alright. Go on – is that right have a turned it off?

4 **Researcher** - No it’s on – yeah – so like the whole point is to try and pretend that you don’t
5 know who I am and that I don’t know anything about health care or anything like that, do you
6 know what I mean?

7 **Participant** – oh right yeah alright.

8 **Researcher** – Erm if we start with what a typical working day is
9 like for you here?

| |
|---|
| Describing the daily routine List like Routine Perhaps highlights importance of routine for dementia residents? |
|---|

10 **Participant** – Well obviously we come in, first thing is to hand over from the previous shift so
11 you know what’s going on. Er when you think you know everything and you’re prepared, on a
12 morning shift its basically going in to everyone getting them up and washing and dressing
13 them, bathing them if they need it, er see that everybody is alright, when everybody’s up and
14 dressed its cup of tea time, and breakfast time and medication time, after, are we going to
15 elaborate of this, obviously, erm its whatever they have got planned for that morning, whether
16 it’s hospital appointments, podiatry appointments, whether its social therapy, whatever they
17 feel like doing.

18 **Researcher** - And that’s like the same sort of thing every day?

19 **Participant** - More or less – whatever the day, be it hairdressers, you know most times there
20 going doing something aren’t they, social activities.

21 **Researcher** – So how long have you worked here?

22 **Participant** – 24 years

23 **Researcher** – And in your time has it just been residents with dementia or?

24 **Participant** – No I worked on the general nursing unit for erm how many years, 12, 13 years,
25 and I was offered a managers post on the dementia unit, which was
26 a promotion so I decided to take it, I was ready for a change any way.

Similar to interview 3 in that healthcare professionals also have experience with other types of residents with different health conditions

27 **Researcher**- So how long have you worked with dementia for?

28 **Participant**– so on a dementia unit it would be 11 to 12 years, but on the general nursing unit
29 there's also a lot of old people with dementia anyway.

30 **Researcher** – So what is your own personal understanding of dementia?

31 **Participant** - my own personal understanding, it's just deterioration
32 of mental capacity really, dementia is an umbrella term it covers a
33 lot of conditions really.

Quite a formal description of understanding of dementia- perhaps related to nursing side of residential care.

34 **Researcher** – erm could you tell me about any experiences positive
35 or negative about working with residents with dementia in your time?

36 **Participant** - I think to work with people with dementia you have to
37 like people with dementia, I like the demographic because, I prefer

Participant offering personal opinion. Explaining how they believe you have to like people with dementia to enjoy the job. Having a preference with working with older people.

Also describes how you have to have a lot of patience due to repetitiveness of dementia – however incorporates sense of humor also.

38 old people, I've always enjoyed working with old people, that was my thing so to speak, I find
39 them amusing, I find them kind, I think you need a lot of patience, if you haven't got any
40 patience don't bother coming because they can test you

41 **Researcher** – how do they test you?

Perhaps indicates there have been times where the repetitiveness has caused the participant to have some frustration with the repetitiveness giving an example.

42 **Participant** - Erm they can test you with the repetitiveness sometimes, continual receptiveness
43 which you know you can end up bog eyed sometimes, you can be asked the same question 240
44 times and you have to answer it with patience. *laughs*

45 **Researcher** - How does it make you feel when you have to have to deal with these particular
46 challenges like you just said?

Unpredictability in the job role.

47 **Participant** - Every day is different, it doesn't mean that you're going to have the same day
48 tomorrow, I think that's what makes you come back, because you can have a day like that, but

49 the day after will be absolutely something else, you know, it makes you laugh more than it
50 makes you cry I always say.

51 **Researcher** – erm are there times when you took your work home with you? If you have had
52 a particularly stressful day or?

53 **Participant** – Erm yeah, took my work home with me, yeah yeah you can do, it certain things,
54 you can worry about certain situations, I never worry that I've done
55 the wrong thing regarding dementia, because there is no wrong and
56 right thing, it's about the there and then, you have to make a decision in that particular moment
57 and you're not always going to make the right decision, and you if you understand that, then
58 you will be good at your job.

Making decisions on the spot appears to be part of the role of the job when working with dementia residents.

59 **Researcher** - Erm what do you think about maintaining good relationships with residents and
60 what does it mean you?

61 **Participant** – in my opinion, the best way to look after someone with
62 dementia is to have a good relationship with them and to know them,
63 and it enable you to look after them, you get to know how they feel,

Believes having a good relationship is the best way to look after someone with dementia – also explains how getting to know someone can with dementia having practical benefits when caring.

64 in a way you can sometime second guess them, you guess what's going to happen, and that
65 basically because you have looked after them and you know how they tick, and you can also
66 prevent situations, by knowing if you do one particular action, it will lead to this particular
67 actions.

68 **Researcher** – have you got any particular example of that?

69 **Participant** – erm its sometimes about judging people moods, if you see that someone you
70 know is in a certain kind of mood, if you try to perform a intervention, like going toilet, while
71 there in that particular mood, there are going to be consequences, so it's always best to stand
72 back and wait till that mood changes, and that's probably true of quite a few people. You are

73 not going to get anywhere so don't bother *laughs*, don't work them up and don't work
74 yourself up.

75 **Researcher** - Erm so would you say every relationships different with each resident?

76 **Participant** – Yeah it just like everyday life, your relationships with

| |
|------------------------------|
| Elements of personhood here. |
|------------------------------|

77 people who haven't got dementia are all different, so they wouldn't really be any different,
78 there still people, they all got their own personalities, dementia or not.

79 **Researcher** – So how would you describe your overall like relationship with your unit?

80 **Participant** - My unit, with the staff and the?

81 **Researcher** – Yeah, any ways that you would describe it?

82 **Participant** – Erm yeah I think I've got pretty good relationships with most of me residents,
83 erm staff its same as anything, a certain number of people and got to work in an environment
84 and they have all got to get on, but that doesn't always work, you know, in every walk of life,
85 and it's just tackle every issue as it arises, there's always going to be problems, so, you have
86 got to look at it philosophically really.

87 **Researcher** – how do you think, erm, do you think your own relationship with the residents,
88 affects the flow of the working day?

89 **Participant** – Yeah definitely yeah, defiantly.

90 **Researcher**- how would you say?

91 **Participant** – well it's like a said with the dementia, it's the decisions you make there and then,
92 isn't it, I can, looking after them brings knowledge, and the knowledge of how they will react
93 to situations, and it's my job to make sure bad situations don't arise in the first place, I'd say
94 90 per cent of situations can be prevented, so prevent them.

95 **Researcher** – Erm can you talk about a time where you felt you relationship has been positively
96 or negative impacted by circumstances outside of you control as a care-giver?

97 **Participant** – Yeah I understand what you mean, I’m trying to think really, I think, there are
98 lots of positives every day, I’m the type of person, my glass is always
99 half full always, I normally look for positive anyway, Erm I can
100 probably turn a negative into a positive, I’m probably not the best
101 person to ask, I’m trying to think of a negative situation really, I was strangled by a somebody
102 once.

Interesting perspective to have on situations that could potentially be negative.

Participant doubts themselves here

103 **Researcher** – really?

104 **Participant** - yeah , erm and it was down really, we was in a confined space, and he wasn’t,
105 he wasn’t erm sure of what’s going on, and he got really panicky, and he went to attack me,
106 and we went, and it set of quite negative, because he has his hand properly around my throat,
107 and there were two girls who were, they said I’m going to, I’m trying to break his hand away
108 from throat, and I’m karate chopping him, which you have, you know trying to make him, and
109 I was trying to get a grip of his fingers, and I couldn’t because he’s quite a big strong man, and
110 the two girls were actually pulling on his arms to pull him away, and it was in here and he was
111 cornered and erm, but he eventually, and it was a bit, it shocked me more than anything, I
112 wasn’t hurt, I was shocked, and that was negative, and we all just sat,
113 and it was a strange situation really, because he just stopped, I was
114 just sorta, regaining my composure, cos it’s over, and the two girls that were pulling his hands
115 off, collapsed laughing, and I, as I came round, and he was just stood there confused by the
116 whole situation, and I was just like why you laughing, I said to - ‘you face it was so funny’ ,
117 so then I started laughing, and then the man started laughing, can ya
118 see, and I mean it could have been serious, because he had a proper
119 grip of me throat, and that was quite negative. But if them girls hadn’t
120 of started laughing, I could have been umm, you know escalated to this big serious situation.

Perhaps indicating that you have to have a composure as part of the job.

Making positive situations out of negative – how to handle situations has impact. Also the fact the resident was also laughing shows how relationships are important, in avoiding bad situations.

121 **Researcher** – so it’s about how you react?

122 **Participant** – it's about how you handle situations.

123 **Researcher** – so what about experiences that you find satisfying?

124 **Participant** - err, I think there so small, that probably, when blank drinks a full drink, *laughs*

125 so little things more than anything, because you can't expect big things in a job like this, when

126 somebody who hasn't eaten for so long, well eats, when things improve, it not, looking after

127 people with dementia not a lot of things improve, do they, in fact they go the other way, don't

128 they, and it's when , erm it's the little things with dementia, when they suddenly say something

129 and they haven't spoken for weeks, it take you by surprise, when something takes you by

130 surprise like that, or when blank is being particularly nice. * laughs*.

131 **Researcher** – erm if you could describe the ideal relationship with a dementia resident how

132 would you describe it?

Creating a safe relationship between you and the resident

133 **Participant** – that they felt safe, they felt safe.

134 **Researcher** – and how would you describe yourself as a care-

135 giver?

Participant finds it difficult to describe themselves, maybe find it pressuring to evaluate themselves, maybe worried about how they would appear if they said what they think

136 **Participant** – that's an hard question, have to ask somebody else that question *laughs*

137 ermmm I consider myself a good, I'm good, I'm good.

138 **Researcher** – yeah erm, what was it like when you first working

139 with dementia residents to what it is like now?

Shows how dementia has been perceived previously – shows how the understanding has developed over time

140 **Participant** – Erm when I started working with people with what they say now have got

141 dementia, it was always known as senility , old age, erm even as a child growing up, my best

142 friends mum, I realise it now, my best friends mums had dementia, we had to, I can remember

143 being a child, 10/11 and having to go and look for her around Royton and bring her home, I

144 didn't know it at the time but she had dementia, so I suppose I've always been around it, and

145 one of my grandmas, what I see now had dementia, she lived her back bedroom, and she was

146 like the wild women of the jungle, she had wild hair and wild eyes. It's just now more, been

147 given a name, it's been given a condition, and it think it's the buzz word at the minute, it's the
148 buzz condition at the minute.

149 **Researcher** - Has your personality made a difference to how you
150 develop relationships with dementia resident?

When employing someone this participant looks for personality traits rather than qualifications.

151 **Participants** - yeah, one thing that is absolutely vital over any o
152 level or a level or degree is a sense of humour, if you don't have a

Shows relational factors play a role. Sense of humor and dementia have a link when it comes to caring for dementia residents.

153 sense of humour then don't apply, and a sensitive nature, because you can't take anything
154 personal. *laughs*

155 **Researcher** – what are you opinions on person centred care?

156 **Participant** - there's no other way really, you got to treat that, especially with dementia, I'm
157 not sure about other conditions, but there is no other way with dementia, there is no cover all
158 with dementia because every single one of them is different, so you have to deliver person
159 centred care, and that's were getting to know them comes in, once

Again relational components

160 you know them, and you know what makes them tick, and you know what upsets them, then
161 you can look after them.

162 **Researcher** - what do you think are the main issues that affect the
163 relationship between a care giver and a resident?

Trust and safety
Comes with the relationship how to create a safe relationship
Also this participant is showing empathy for the individuals feeling – picking up on distress

164 **Participant** – trust, they have got to feel safe with you, they have
165 got to know that, they have got to know, you have got to keep them happy, and stop them being
166 distressed, there is nothing worse than seeing someone with dementia in a state of distress, erm
167 I think keeping them happy, and knowing that your keeping them safe and that they feel safe
168 with you.

169 **Researcher** - and how do you keep them safe?

170 **Participant** – by knowing them, by knowing what makes them happy, knowing what upsets
171 them, avoiding what upsets them, and knowing what makes them happy.

172 **Researcher** – What do you think about current government policies regarding care for those
173 living with dementia?

174 **Participant** – it's all about money in the end, erm at the moment, I think it will be forgot, I
175 think it will be something else next year, because that's how it goes with the NHS and the
176 government, I think that I hear this talk about a cure, and I don't, personally think there will
177 ever be a cure, I think it's a condition that has to be managed, so I tend to think that people are
178 being a bit miss leaded when they say they want to put research into dementia to find a cure
179 for dementia, because I think it's just a part of old age, and there will be a lot of PC people who
180 won't like me for saying that.

181 **Researcher** – no no, erm what do you think care-practices will be like in another 5-10 years
182 from now?

183 **Participant** – Erm exactly the same as they are now.

184 **Researcher**- Why do you think that is?

185 **Participant** – Because there is no money, basically there is no money, the population is
186 becoming more aged, there's going to be more pressure, so I don't think there will be much
187 improvement, but let's hope they don't get any worse.

188 **Researcher** – what do you think relationships will be like between
189 care-giver and dementia patients in another 5 or 10 years' time?

| |
|---|
| Maybe indicating that there needs to improvement for training. |
|---|

190 **Participant** – Erm I think if the training improves, and I think if every dementia unit, I think,
191 erm, if, if they attract the right staff, I don't particularly go for educated girls, I go for girls with
192 a nice personality and a sense of humour, and it can, and training and training, and I think were
193 a unit who has a lot of involvement with families, encourage families to not to opt out of the
194 care but to opt more in, you know, cos it has to be a job for all us, not just us. You know,
195 encourage families, encourage them to get involved, I mean we have got good families at the
196 minute, families I think they need more help at home, you know, they need more GP input, I

197 think medication has a role, and it's alright people saying you know, oh its cosh, it's a medical
198 cosh and all that, I think it improves life, you know. I'm not talking
199 about you anti-psychotics, I'm talking about your citalopram's, and
200 your donepezil's, you know and your memantines, erm and just managing the condition, and I
201 think give families more support at home, you know where, there not up all night, up 24 hours
202 a day, because the families are becoming exhausted, and to give them more help and many not
203 as many would have to go into care, but there's my frustrations it's just the lack of
204 understanding by GPS.

Managing symptoms with medication appear to be a factor this person believes will improve quality of living.

205 **Researcher** – ah Right, so why do you think that is?

206 **Participant** – Because they don't know anything about dementia,

207 **Researcher** – ah you would think they should know?

208 **Participant** – oh yeah, they should know, the training in the GP is not particularly good these
209 days is it, erm and I think a bit more support for the family, a bit more education for the families.

210 **Researcher** – what sort of support do you think the families need?

211 **Participant** - Medication for a start, if you have got a dementia
212 patients who's up all night, it's not because their meaning to be up
213 all night, it's because they have lost the concept of night and day,

Trying to tackle the issue with how residents lose the concept of night and day. Trying to reduce the pressures of dealing with this as a care – giver.

214 they don't know the change any more, some medication helping them to sleep, more day
215 centres, so if they get that break, you know because we do it for 8 hours a day, we be able to
216 do it for 24 hours a day? Would you be able to do it for 24 hours a day?

217 **Researcher**- no

218 **Participant** – no I wouldn't, so we except families to do it, don't we, just the day centre a
219 massive help, but there shutting them all down because of lack of money, just some respites
220 now and again where they can go in for some where for one night a week, or two nights a week,

221 so they can get one night a week's sleep, you know their exhausted, I mean we do it three shifts,
222 whereas if there at home they have to do it all by their selves.

223 Researcher – so you think it's harder for domiciliary care, do you think it's, its need to be more
224 of that, or do you think their safe coming to a home?

225 **Participant** - I think it there is no family support they are safer in a home, I mean the
226 domiciliary carers are under a lot of pressure all the time, they get the short end of the stick
227 really and they have to do what the company tells them to do, you know erm, but you get these
228 little old ladies living on their own, with no family what so ever, who get a visit for ten minutes
229 in a morning and ten minutes at night, by the time if they got full on dementia ,by the time ,
230 they don't know what you're doing they don't know why your there and then where have you
231 gone, you know, why are you there? They got to deal with you for ten minutes then you're
232 gone, how they supposed to ever understand that? You know, and the domiciliary carers say
233 make sure their clean make sure they have been on the toilet, give them a toast and a cup of
234 tea, leave it with them and just pray that they eat it, what kind of a situation is that? Would you,
235 you know you'd get sent to jail if you treated a dog like that.

236 **Researcher** – that's everything thankyou

237 **Participant** – Was it alright *laughs*

1 **Interview 5**

2 **Researcher** –What’s a typical working day like for you?

Elements of judging peoples moods again –
indicating an individual’s mood can affect
the day

3 **Participant** – Every single day can be different it depends what moods people are in, some

4 people can be in a happy mood so the environment can be happy

5 and people could be miserable, it all depends every single day is

6 completely different.

Elements of judging peoples moods again –
indicating an individual’s mood can affect
the day

7 **Researcher** – Erm what sort of residents have you worked with in you time working in care?

8 **Participant** – Erm every single person is different, erm with, I’ve

Individuality / personhood

9 worked with so many different sort of people, with different stages

10 of dementia, like early stages to people that have no capacity, to

11 people that have no, forgot what it’s called. *pause*

Maybe some nervousness here – hesitation
participant appeared to doubt herself in what
she was saying, unsure as to why this may
have been.

12 **Researcher**- it’s alright erm – so with that in mind what’s your

13 typical understanding of dementia and how might this impact your

14 working day?

Uncertainty

15 **Participant** – Erm

16 **Researcher** – like how do you understand dementia, how would you describe it to someone

17 who doesn’t know what it is?

18 **Participant** - Erm there’s different stages and different forms of

Demonstrates how dementia affects
individuals in so many different ways.

19 dementia, so there can be people where you just have to be repetitive with them, there are some

20 who physically can’t do anything, and there some with no capacity to do anything and then

21 there’s people are just, forget the odd thing, so it depends on the person and there’s different

22 stages that they are at with the dementia.

23 **Researcher** – could you talk about any experiences positive or
24 negative about working with residents with dementia? And
25 examples?

Uses the term we as opposed to herself in these experiences. Perhaps linked to the work force around her/ or even the individuals with dementia. Suggests maybe something to do with how the experiences are experienced by not just

26 **Participant** - we have had quite a few experiences, to people trying
27 to use the wall the light a cigarette, and people completely not

The physical symptoms of dementia – the confusion they go through. The care-giver experiences the confusion with them

28 knowing where they are, so the confusion comes in there, erm we have had certain residents
29 that think there on holiday, we have certain residents who are completely oblivious to the
30 surrounding around them, but like a say it just depends on the stages of the dementia that they
31 are at.

32 **Researcher** – yeah – erm how it make you feel when you have got to deal with these particular
33 challenges like you have just said?

Some uncertainty here – however pauses for thought and confirms her thought process.

34 **Participant** – I just go into it open minded and erm.

Perhaps indicating this is part of the job role – you have to be this way for various reasons.

35 *pause*

36 **Participant** – yeah you got to be open minded about everything,
37 some things can be emotional and make you sad, like certain things
38 can happen, that can be emotional, and sometimes like you become
39 their friend, so like, when they feel sad you feel a bit sad and erm
40 when your happy, they become happy, you do what you can to try
41 and make the positive about like the negative that's going on.

Quite vague here – however could be a reason for this – perhaps some situations may be difficult to talk about openly.

Own thought on this – 'care-givers often have to suppress their feelings, in order to get jobs done. Especially in cases of perhaps deaths, illness worsening etc. Even though naturally they put emotion toll on the care-giver, the care-giver has the underlying knowledge, that as a care-giver, part of your job role is to not allow yourself to become attached, due to the nature of the role. However – this is perhaps easier said than done.

42 **Researcher** – Erm do feel like any of these particular, like you say
43 you can feel sad and that, do you take stuff here home with you?

Become their friend – a familiar face. To ease what's actually happening. The connotations of the reality of dementia is quite negative – the care-giver has a role to be positive and make the most out of a negative situation.

44 **Participant** – I know personally, you shouldn't take anything home
45 with you, but were only human our self aren't we, I find it

Again suppression of feelings. Conflict between the knowledge and reality of being human.

46 emotionally distressing sometimes, the things that go on, so
47 sometimes I go home and think about what's happened in my day,
48 but I know that personally I can't dwell on it, because I know that it's not affecting my life is
49 it?

Work and home life try to remain two separate entities.

50 **Researcher** – what do you think about maintaining good
51 relationships with dementia residents and what does this mean to
52 you?

Interesting word choice here – it is nice to have a good relationship with them. Positivity.

Like normal relationships- trust is built, like friendships build over time.

53 **Participant** – I have – it's nice to have a good relationship with them, for them to build that
54 trust, to build that trust with them, erm and it, it's nice for them, like
55 a said, for them to feel like they have got a friend, to make them feel
56 like they're not alone, there is many roles to our jobs, we become their friend the family, the
57 hairdresser *laughs*, we do everything.

Many roles to the paper definition of a care-giver. Pragmatically – care-givers give and do a lot more than you would think. They give a lot of their selves to these residents

58 **Researcher**- so you said every relationship different didn't you? So
59 how would you describe you own relationship with the residents?

This participant creates an image of what they would like to be to the residents and focuses on being positive. Interesting how this person uses the term like to be instead of I am that person. Maybe some reason for this- could have been explored more? Why would you like to be that person, what's stopping you being that person?

60 **Participant** – I like to be like the positive person, I like to make
61 them smile, like crack a joke, cheer them up, because it's not like the happiest environment for
62 people to be in, so the best thing you can do is try and make, make it more positive.

63 **Researcher** – do you have any like strategies that you to
64 communicate, to help you complete like tasks and stuff like that?

Attention to detail, picking up on other social ques which will aid interaction and communication.

65 **Participant** – For people that can't speak, I genuinely just try and listen more, so you try to
66 listen more to see how they try to communicate, and sometimes you try to communicate the
67 way they can understand you, so yeah..

68 **Researcher** – Can you talk about where you have felt you
69 relationship with a resident has been positively or negatively
70 impacted by circumstances out of your control?

Care-giver experience bereavement quite regularly, this must be difficult to comprehend. Especially as this individuals says they spend every day with these people. By saying it's very hard – perhaps this refers to the emotional side of the job- managing your emotions on a daily basis for the benefit of other people.

71 **Participant** – erm, I'm trying to think, there's been many things
72 where like people have passed on, and you deal with these people every single day, near
73 enough, so it is very hard not to get attached and like they become part of your day, I see a lot
74 of these people more than my own family and friends so it very very hard.

75 **Researcher**- so what experiences do most satisfying about the job?

Taking pride in knowing that this person has contributed to helping someone live their day to day life. Realising that we do take out own abilities for granted.

76 **Participant** – knowing when I've gone home, when I go home I
77 know that I have helped 12 people today and I've helped people just do there day to day things
78 that we take for granted and I know that , it's nice to know that you have helped someone, I
79 get satisfied from that anyway.

80 **Researcher** – if you had to describe the ideal relationship, how would you describe it? What
81 sort of way would you describe it?

Big theme coming through is getting to know the resident

82 **Participant** – The relationship between me and a resident? The ideal relationship is to get to
83 know them, get to know what they like, get to, to, we have the time to get to know them
84 personally, we have that advantage, don't we, we get to know them personally, because we get
85 more time with them, so we get to know what they like, what they don't like, what, if there in
86 a bad mood, we can just look at them, and know they are in a bad mood.

87 **Researcher** – How would you describe yourself as a care-giver?

88 **Participant** – Myself erm, positive! I think I am quite a positive person.

89 **Researcher** – what was it like when you first started working with dementia residents to what
90 it's like now?

91 **Participant**- when I started I was walking into the complete unknown, didn't have an absolute
92 clue, and all I did really was get to know the routine of the home, and then get to know them
93 individually, and get to know their personal needs.

94 **Participant** – sorry- my drinks bloody awful *laughs*

95 **Researcher** - *laughs* so do you think your personality makes a difference to how you form
96 relationships with dementia residents?

97 **Participant** – 100 per cent. Definitely.

98 **Researcher** – how would you explain that?

Initiating that connection, curiosity of the person – finding mutual connections.

99 **Participant** – I feel like I'm quite a chatty person anyway, so if I have a spare five minutes,
100 I'll go and engage in conversation with them, so

101 **Researcher** – so chatty?

Curiosity

102 **Participant** – yeah chatty, erm, I talk, I ask them a lot of questions about their life and I ask
103 them like, I ask them what they used to do, I find out a bit about them, so then we can find like
104 mutual things in common then can't we, and then we can engage in a conversation about that.

105 **Researcher** – Erm what do you think, what are your opinions on person centred care?

106 **Participant** – I do know what it is, but I don't know what it is?

Scattered understanding of person centred care – knows this person knows what it is – however find difficulty in describing it.

107 **Researcher** – like offering choice sorta thing and all that sort of stuff?

Perhaps indicates that pcc covers a lot of aspects of care its quite difficult to understand maybe

108 **Participant** – oh yeah so if someone got capacity, erm still ask them

109 the question, still ask them, just because they can't verbally communicate with you, doesn't
110 mean that they don't know what is going on, so we just ask them anyway.

111 **Researcher** – what do you think are the main issues that affect the relationship between a
112 caregiver and Resident?

- 113 **Participant** – Erm sometimes they can be violent, it depends, if
 114 someone frustrated and you go over to them with like an
 115 aggressive tone, that's going to make them worse isn't it, so you have to kinda, I personally if
 116 someone's, I would stay calm, and reassure them, reassure them that everything is ok and make
 117 them feel more calm and at ease.
- 118 **Researcher** – yeah – what do you think any government policies regarding care for dementia
 119 residents?
- 120 **Participant** – a lot of the legislation that is in place is right to be honest, but a lot of it is
 121 unnecessary, cos it, with a lot of the legislation and paper work that we have to do is taking up
 122 a lot of our time, so we can't personally give the 100 per cent care that we need to give them.
- 123 **Researcher** – what do you think care practices will be like in
 124 another 5 or ten years from now for residents with dementia?
- 125 **Participant** – Hopefully – better paid. *laughs* hopefully if the
 126 pay was better, personally I think there would be a lot more people
 127 willing to do it, I think it takes a certain type of person to do the
 128 job, erm and it think, it take a certain person to do the job and it
 129 takes a certain kind of, dunno what I was gonna say, delete that bit
 130 haha.
- 131 **Researcher** – that's fine. It's the last one – what do you think relationships will be like in
 132 another 5 or ten years from now between care-givers and the resident?
- 133 **Participant** – I think that there is that much legislation, I think it will
 134 just be made professional, and I think people won't have time, and the

Again judging moods, remaining calm, best ways to handle situations.

Very interesting point –paper work holding back the time spent with the residents.

This participant doesn't actually mention anything about the residents with dementia here- focusing on the care-giver perspective, indicates maybe this holds high importance to this person, perhaps feels strongly about the pay for care-giver, hence feels its vital to mention it. This individual shows some form of perhaps regret in what she was saying as she ask the researcher to delete this bit, interesting as to why she may have said this?

Perhaps this care-givers feels the needs of care-givers are not being met appropriately, therefore instantly focuses on this aspects of the question.

Again another interesting perspective of what relationships look like in the future, the idea that it will become professional, perhaps suggesting that care is more personal at the moment? Maybe referring to the hospital side of things, as hospitals and care homes are quite different in their approach to care.

135 way it's going now I think it's just a money maker, and people don't actually think that these
136 are actual human beings that we are dealing with.

137 **Researcher** – that's really interesting thank you. Thank you for your time

138 **Participant** – you welcome any time

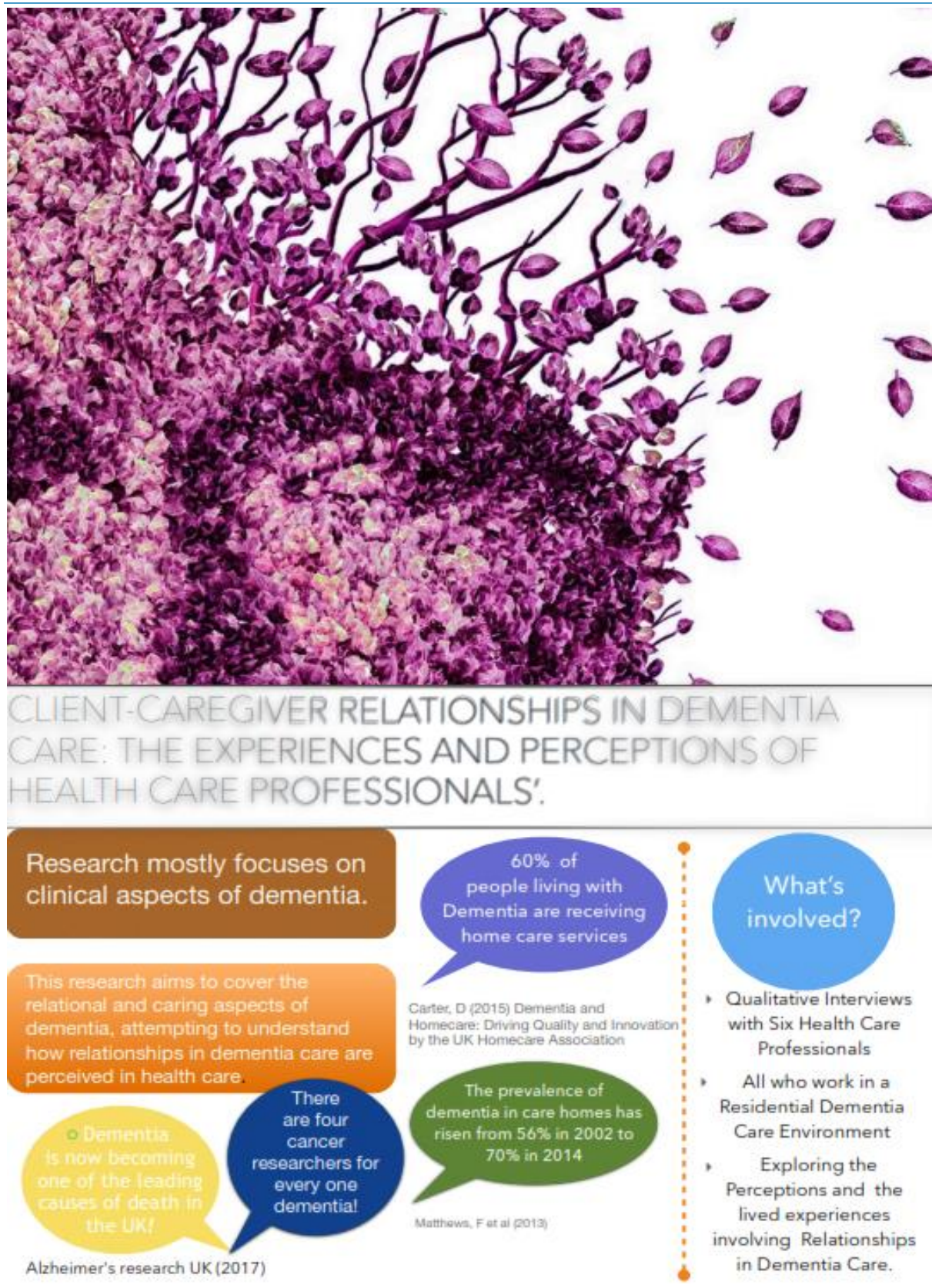


Figure 3- PGR Conference Poster