

**An Exploration into the Experiences of the Care Assistants Working
with the Sufferers of Dementia.**

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS	3
ABSTRACT	4
1. INTRODUCTION	5
1.1 Illness of Dementia	5
1.2 Social Care Work with the Sufferers of Dementia	7
1.3 Stress within the Workplace	11
1.4 Education/Training of Care Assistants	13
1.5 Work Burnout of Care Assistants	15
1.6 Value in the Workplace	16
1.7 Introduction Summary	18
2. METHOD	19
2.1 Design	19
2.2 Materials	20
2.3 Apparatus	21
2.4 Sample Participants	21
2.4.1 Sampling Methods	22
2.5 Procedure	22
2.6 Data Analysis	24
2.7 Ethical Consideration	25

3. RESULTS	27
3.1 Introduction	27
3.2 Stress of Care Assistants	27
3.2.1 <i>Causes of Stress</i>	27
3.2.2 <i>Coping Mechanisms</i>	28
3.3 Work Burnout	30
3.4 Aggression in Dementia Patients	31
3.5 Value in the Workplace	32
3.6 Staff Morale	33
4. DISSCUSSION	35
4.1 Stress of Care Assistants	35
4.2 Aggression of Dementia Patients	38
4.3 Value in the Workplace	40
4.4 Limitations	41
4.5 Suggestions for Future Research	42
4.6 Conclusion	43
REFERENCES	45
APPENDICIES	50
Appendix 1: Information Letter	50
Appendix 2: Consent Form	52
Appendix 3: Interview Schedule	54

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ABSTRACT

The aim of the research was to explore the experiences of the care assistants working with the sufferers of dementia. In order to answer the research question “how does care work with dementia sufferers affect the care assistants, a qualitative method was adopted. Eight in-depth semi structured interviews were conducted using an all female sample. The interviews were analysed using thematic analysis, aided by Nvivo 10 software, in which five main themes of the study were identified. The findings of the research portrayed a variety of both shared and individual experiences of the care assistants, highlighting the diversity surrounding dementia care. The researcher found both similarities and disparities when comparing past research results to the current research findings, which are discussed in detail within the discussion section of the research. A variety of limitations and recommendations for further research are addressed in said section.

1. INTRODUCTION

The topic which has been chosen for the final research project is the incurable illness of dementia. Dementia is a progressive condition which has no single cause or cure, and deterioration is likely to occur in all domains (Cahill, O'Shea and Pierce, 2012). The aim of the research is to explore the experiences of the care assistants working with the sufferers of dementia, focussing on the individual and shared experiences of the care practitioner and the ways in which they have been affected. The literature review will begin by giving an outline into the illness of dementia, following on to discuss what is involved in social care, including the roles of the social care worker. From here the literature review will discuss a variety of issues surrounding dementia care such as aggression of patients, stress in the workplace, work burnout, education and training of care staff and the value of care staff in the work place. The research was carried out using a qualitative method with semi-structured interviews, which will be discussed in the method section. The findings of the study will be addressed in the results section, highlighting the main themes that were developed through the study and will then be analysed further in the final section of the research, the discussion.

1.1 The Illness of Dementia

In order to gain an understanding of the effects of this crippling disease on the carer assistants of the sufferers of dementia, one must first look at understanding the disease itself. Dementia is a serious memory and psychiatric disorder that affects not just the person with dementia but also the people closest to the sufferer. The illness of

dementia causes the sufferer to experience situations of powerlessness and estrangement, placing them in a confusing and frightening place for both themselves and those closest to them (Miesen, 1999). The clinical syndrome of dementia refers to a pattern of cognitive deficits characterized by impairment in memory and at least one other cognitive domain (e.g. Language, executive functions, and visuospatial abilities) that is sufficiently severe to impact the behaviour and interfere with social or occupational functioning (Wierenga and Bondi, 2011). It is an extremely important social issue and has become exceedingly topical over the past number of years; there are over 44,000 people living in Ireland with a form of dementia today. The number of dementia cases in Irish society is increasing exponentially, with an average of 4,000 new cases arising each year, with numbers exceeding those of cancer and heart disease. This is expected to increase significantly over the next 30 years to almost three times the number of incidences at the present (Marketing and Communications Office, NUI Galway, 2012).

At present, it is not known what causes the different types of dementia; medical research is ongoing throughout the world to discover the cause and develop new treatments (Alzheimer's society of Ireland, March, 2012). The journal of the American society on The Journal of the American Society on Ageing gives an insight into the illness of dementia explaining that Alzheimer's is the biggest cause of dementia, accounting for a staggering 60% to 80% of all dementia cases. These figures illustrate how apparent it is for research to be done in the field, in order for a deep and clear insight into possible cures for the illness to be found and for the most successful ways to manage patient care and to manage the physical and mental well being of the people caring for the sufferers to be discovered. The percentage of those

whom suffer with dementia and require care increases with age. 30% of those aged 65-69 to 66% of those aged 90 and over suffer, and is nearly double for those who require high amounts of care (62%) compared to those needing low levels (34%) (Prince, Prina and Guerchet, 2013, p.26). Unfortunately there has been very little research done on the affects caused to the people closest to the sufferers, with the vast majority of previous research being based on family carers rather than addressing it from a professional caring side. Previous research which was carried out in Canada highlighted the lack of research being done in the field. The report highlighted that despite the fact that caring for people with dementia can increase burden on and lead to depression for the care giver, very little research has examined concerns about them developing the condition themselves (Alberts, Hadjistavropoulous, Pugh & Jones, 2011). Although this does show that some research is being done, it is very limited in its findings, as the research is very narrow and fails to address the bigger aspects of the experiences of caring for the sufferers of dementia.

1.2 Social Care work with Sufferers of Dementia

The role of the social care worker is the care, protection, support and welfare of their clients. They must have a wide range of skills both personal and intellectual, requiring the knowledge to work not just alone using their own initiative, but also as part of a team. The individual characteristics of a social care practitioner are of paramount importance, and will determine a person's suitability and ability to fulfil a meaningful role in this profession, such as "reliability, trustworthiness, altruism, empathy, compassion and maturity" (Share and McElwee, 2005, p.10).

Caring for a person with dementia requires a holistic approach as it is not just care or supervision that's needed but also a provision of non judgemental relationships between not only the care giver and the sufferer but also with the family members of the sufferer. Carers have to deal with a complicated interplay of relationships not only between themselves and the sufferers but also the behaviour between the sufferer and their own family members. The carer must also deal with their own feelings and behaviours towards the patient and how they feel the family members behave towards the sufferer while at the same time they must be conscious of situations of transference and counter transference and endeavour to remain impartial (Jones, 2004, p.406). In conjunction with this the carers must also work alongside their colleagues both individually and as a team. A deeper understanding and acceptance into the diverse patterns and aspects of these relationships is needed to create the levels of care which will be most effective in meeting the needs of the person with dementia (Miesen, 1999, p.109 & 110). In order for this level of care to be maintained it is of utmost importance for the carer themselves to look after their own health and mental state.

Care-giving in dementia is a special field of its own that requires multi-disciplinary cooperation as a basic criterion (Jones, 2004, p.414). There are many different aspects involved in this form of caring with the care-giver having to undertake many different tasks and roles. It is extremely demanding work surrounded by both positive and negative aspects; however it is the negatives that are too often portrayed, with the majority of research highlighting the negative strenuous side shadowing the positive aspects that are involved. The carer's role is extremely changeable and complex, dealing daily with such issues as confrontation, irritating

behaviour, communication problems and requests which cannot be fulfilled making such work evidentially challenging and exhausting. The term burden is used more often than not to describe the care that is required, with the high levels of demand being the main cause behind it. The demands placed on care-givers create numerous health problems both physically and emotionally. “Care giving is often associated with the sense of being captive, burdened and distressed” (Cummings, 2003 p.282). The term burden is most often associated with the physical, psychological, emotional, social and financial aspects involved in caring.

Caregiver depression and anxiety has been directly linked to the agitated behaviours of the patient, with the carer ranking behavioural disturbances among the most distressing issues that are created through caring for a sufferer of dementia. (Cummings, 2003 p.282). “It is known that cognitive problems are associated with aggression towards people who care for the older person, especially if they are experiencing pain or perceive that they are being restricted in their activities (Drennan, Lafferty, Treacy, Fealy, Phelan, Lyons and Hall, 2012 p.71). Aggressive tendencies can be linked to the person’s personality before the onset of dementia; however this does not prevent those who have never been aggressive before from developing this type of behaviour (Alzheimer’s Society, 2013). A previous study conducted on the aggression of dementia patients of 200 care homes across the UK, highlighted the alarming rates of aggressive behaviour among the sufferers of dementia. The study identified that 73 per cent of the participants had evidence of dementia patients being verbally or physically aggressive, with a staggering 89 per cent of staff being distressed by the behaviour of dementia patients and stated that they had only reached the tip of the iceberg (Alzheimer’s Society, 2006). However,

although this study revealed aggressive behaviour among dementia patients, these instances of aggression are very rarely recorded by care assistants as it is just seen as an unavoidable part of their job. Conflicts between staff and residents happen for a variety of reasons such as misunderstandings and invasion of personal space which in turn can lead carers to associate violence with their job as a natural consequence, as some of the events can be seen as impossible to solve. (Drennan, et al., 2012, p.71).

Research undertaken by the Bradford Dementia Group, “Irish family carers’ experience of their relative’s transition into a nursing home”, illustrates further the demands created through caring for a dementia patient. The report effectively highlighted the round the clock demands placed on the carers which took up all of their time and in turn made them incapable of switching off from their role as a carer and continuing on with their own lives; with one of the participants stating that “I could never sit down and say its my time I was on call 24/7” (Argyle, Downs and Tasker, 2010, p.12). These practical ‘burdens’ created through caring resulted in the majority of the participants stating a decline in their own health. The demands put on the carers led to mental health problems such as stress and depression, in turn making the task of caring for their loved ones enormously strenuous and practically impossible. The research report “Creating excellence in Dementia Care” strengthens the apparent pressures placed on caregivers stating that “in reviewing the research evidence for this report a substantive body of published literature was found demonstrating that caring for a person with dementia compared with other caring roles, places much greater demands and strains on the family members” (Cahill, O’Shea and Pierce, 2012, p.13).

Although there are many negative points surrounding care giving there are also positives involved such as thankfulness, dependency, honesty and spontaneity all of which help balance the difficult aspects of this work. Something as simple as a patient smiling through satisfaction of the care and attention which was given to them, the sufferer working along with the carer and reacting to things the carer does and also the person with dementia expressing themselves to their carer each create many positive feelings which encourage carers to continue their work. This is all based on a trusting relationship (Miesen, 1999, p.108&109).

1.3 Stress within the Workplace

Stress has always been a factor in human health throughout history; however it is becoming a more serious problem in the modern day world. It has been concluded that between 75 and 90 percent of all diseases prevalent in the western world are in some way related to stress. Whether caused directly or indirectly, it still affects a person's prolonged stress and its physiological impact (Berry, 1998, p.416). Stress can be defined as “a negative experience/feeling, associated with new physical symptoms” (HSA, n.d.).

It can be said that people misinterpret the roles and pressures that a career in caring creates. Some people don't identify caring as actual work but rather as ‘babysitting’ with no skills required, with stress not even being recognised as a distinguishing factor. Although it is not always recognised, caring is in fact a career which requires ‘work’ and creates its own “stressors” and challenges for the individual carers.

Work whether paid or unpaid can be defined as “being the carrying out of tasks requiring the expenditure of mental and physical effort, which has as its objective the production of goods and services that cater to human needs” (Giddens, 2009, p.886). In terms of stress within the work place there are many determining factors which trigger stress, for example working hours, working conditions, work overload/under load, role ambiguity, role conflict, relationships in the work place and career development. Work stress can be defined as “the process that arises where work demands of various types and combinations exceed the person’s capacity and capability to cope” (Arnold, Randall, Patterson, Silvester, Robertson, Cooper, Burnes, Swailes, Harris, Axtell and Hartog 2010, p.435). Modern theories of work related stress identify a negative emotional state that is the result of interactions between a person and their environment. The stress is created or made worse through work itself, contributing to a range of issues within psychological, physical health and organisational health (Arnold, et al., 2010, p.435).

Relationships within the workplace are a major factor in stress caused through work. Support in the work place has a significant positive impact on employees; however when a support system fails within the work environment, relationships become frayed and damaged. Friction, anger and disagreements arise which create stressors (Arnold, et al., 2010, p.461). Damaged work relationships are made extremely evident through role conflicts which become apparent through conflicting job demands such as, “employees who are expected to do thorough and creative work, and at the same time meet sharp deadlines, often feel role conflict” (Berry, 1998, p.434).

According to the Health and Safety Authority (HSA, n.d.) the effects of work related stress on the individual are categorised as mental, physical, behavioural and cognitive. The majority of people react differently to stress and develop individual coping mechanisms, however contributory factors such as age, personality, mental state and gender play a role in how a person deals with the stress caused within their life. In the area of dementia care understanding, behavioural and psychological symptoms of dementia (BPSD) is of paramount importance. BPSD consists of five syndromes: psychosis, aggression, psychomotor agitation, depression and apathy. A report carried out in Sweden identifies the links between stress and BPSD suggesting that the effects are not only relevant to the patient but also the caregiver (Kristansen, Hellzen and Asplund, 2006, p.245). A study conducted by the Alzheimer's Society of Ireland found that contributors to care assistant stress included a lack of preparation to provide care and a low self-efficacy in the carer's ability with the resulting stress impacting on care assistant's job satisfaction and also creating an increase in the turnover of staff. (Zimmerman, Williams, Reed, Boustani, Preisser, Heck and Sloane, 2005, p.97).

1.4 Education/Training of Care Assistants

The lack of training and education that is available to carers to understand the correct measures to deal with dementia patients is a serious contributory factor in stress among care assistants. Social care is an occupation with some status and one that requires access to a specific body of skills and knowledge (Share and McElwee, 2005). These skills are not solely obtained through academia, but also require the individual to have interpersonal and social skills, and have the capability to reflect on

one's own weaknesses. This poses a challenge for the student to develop and evolve professionally, as the need to constantly look at one's own strengths and weaknesses in relation to their work. This poses the debate are social care practitioners born, or are they trained?

Social care practitioners must maintain a professional demeanour in order to provide high level of care to their clients. To do so the social care worker must obtain both necessary training qualifications, academically and socially, and more importantly develop the ability to observe themselves in interactions and improve their to put words around what is happening. Once they have acquired this skill in the situation, it enables them to be much more creative and purposeful in how they use themselves (O'Connor, 2006). The education and training of staff should not only emphasise the physical aspects of the job, but also consider incorporating the psychosocial aspects such as effective communication, dealing with aggression and stress reduction (Goodridge, Johnston and Thomson, 1996).

There have been several reports which have played an influential role in shaping the development of social care in Ireland. The Kennedy Report played a major role in the decision of what types of education and training should be available to social care practitioners, which led to changes in the skill set of practitioners. Currently, the minimum educational requirement to enter into the caring profession is a module from The Further Education and Training Awards Council (FETAC) pitched at level 5. Most commonly obtained is a FETAC level 5 elective module "Care of the Older Person". This module is a minor component award leading to a full FETAC level 5 Certificate in "Healthcare Support". While this module is hugely beneficial to

the carer, it is not specific to dementia care and does not include either a compulsory or elective dementia care module (FETAC, 2004). In order to advance further with dementia training, the carer can do so either through in house training provided by management within the organisation they work for, or seek private training programmes delivered by specialists, such as SONAS aPc (SONAS, n.d.). Once again this demonstrates the lack of specialised knowledge in dementia care which can possibly lead to stress and burnout within the workplace.

In the ever changing turbulent environment which social care professionals must operate, the demand for continuous professional development is extremely apparent, therefore more experience and skills are needed to allow them to adapt to the constant changes and demands in the role of a social care practitioner.

1.5 Work Burnout of Care Assistants

Burnout is the result of physical, psychological and emotional exhaustion. Burnout can be described as a metaphor for the draining of energy, or in other words the smothering of a fire or the extinguishing of a candle - thus the fire cannot continue burning unless there are appropriate resources that keep being restored (Schaufeli, Leiter and Maslach, 2008). The most common side affect of burnout as mentioned above, is exhaustion. Physical exhaustion affects people's energy levels creating circumstances of physical strain, for example frequent headaches, poor sleep and changes to diet. Emotional exhaustion, more often than not will trigger depression, which in turn leads to the feeling of helplessness and feelings of being closed into one's job. However the most severe element of exhaustion is the physiological side,

which creates a state of mental exhaustion or depersonalisation. This places a person in a negative mindset, turning people away from their job or organisation, derogating themselves and in some circumstances life in general, creating a direct link to feelings of low personal accomplishment (Furnham, 2005, p.390).

The pressure and demands placed on the care assistants caring for dementia patients directly link to burnout amongst care staff. The level of commitment and workload that is necessary for carers to look after dementia patients at a high standard requires serious levels of determination and discipline. Burnout among care assistants presents a significant and immediate threat to the balance of care for people with dementia. Previous studies have highlighted burnout within care staff indicating that 69% of care assistants looking after patients in the late stage of dementia will have to provide 14 hours or more of care a day, thus portraying the significant risk of burnout caused by overload and emphasising the need for interventions directed to the carer (Trepel, 2007, p.7). Looking from a broader perspective, a study conducted in Japan on burnout of care professionals illustrated the difficulty in maintaining professional care giving staff due to the level of burnout within the sector. The study highlighted the importance of the relationship between coping mechanisms, personality and burnout (Nuramoto, Nakamura, Kitabayashi, Shibata, Nakamae and Fukui, 2008, p.174).

1.6 Value in the Workplace

Social care is provided to those who require assistance and support for many different reasons and in various locations such as the home, in the community and in

residential settings. The Health and Social Care Professionals Act (2005) has placed a demand on the various stake holders to professionalise the social care worker. Professionalization can be defined as “a process whereby an occupational group is able to claim special or particular, status and power for itself” (Share and McElwee, 2005, p.42). Given our current economic climate, increasing unemployment and rising drug and alcohol addictions the need for social care in Ireland and necessity for the professionalisation of social care is extremely evident. However the hesitancy to identify social care work as a professional career is still very much visible. This can be argued for numerous amounts of reasons; however the major component in the issue is the de-valuation which is placed on care assistants. The career as a whole can be seen as very segregated, especially through gender. Occupational gender segregation refers to “the fact that men and women are concentrated in different types of jobs, based on prevailing understandings of what is appropriate ‘male’ and ‘female’ work” (Giddens, 2009, p.906). Caring jobs are overwhelmingly held by women and are illustrated as a female’s role; the typical mother figure.

According to a Swedish journal carried out in 2006, care assistants interpretations on how they were valued in the work place reflected feelings of “regarded as a burden” and “being insignificant”. The majority of the participants felt that the organisation they worked for did not value them, saying that they felt no power to influence change. Others said they felt subdued which led to feelings suggesting that they may as well give up. “Feeling uncertain” was also mentioned in the context of how negative situations including specific types of behavioural disturbances such as “continuous rudeness, being spat at, being scratched or physically hit by residents, without responding physically themselves to such

provocations” left them feeling unable to cope and in some situations feeling that the best course of action is to leave the room to regain a sense of control (Kristiansen, Hellzen and Asplund, 2006, p.250). Current research on dementia care suggests that it needs recognition within organisations and should be identified as a highly skilled position (Cahill, 2012).

1.7 Introduction Summary

The aim of the research was to answer the general research question “how does care work with dementia sufferers affect the care assistants” by exploring the experiences of the care assistants who work with dementia patients. The reasoning behind choosing this as the area for research was to gain a deeper and clearer indication of the affects which are brought about by dementia.

In exploring previous research that was undertaken in the field of this topic, it was seen that the main focus was based on the family carers’ perspective, whereas this study was to investigate the care of dementia patients on a professional level outside of the family unit. This was chosen to get an insight into the effects of caring for dementia patients outside of blood ties and through a different form of relationship.

2. METHOD

2.1 Design

Due to the exploratory nature of the study a qualitative method was adopted in order to answer the research question: “how does care work with dementia sufferers affect the care assistants?” A qualitative approach was deemed the most suitable for a variety of sections throughout the research such as the research design, the data analysis and the data collection as qualitative is narrow and supplies in-depth data. A qualitative method was more relevant than a quantitative approach in conducting the study, as qualitative research gathers an in-depth understanding of individual actions in social life whereas quantitative research sets out to gather research using mathematical modes and statistical analysis (Giddens, 2009, p.49).

A Qualitative method proved to be the most successful in answering the research question as it provides the researcher with a better understanding of the care assistant's experiences of caring for a dementia patient. A qualitative approach places the researcher in “close contact with the research object and is able to gain a more profound understanding of the field of research as well as to discover insights and meanings about human health conditions and behaviours” (Rundqvist and Severinsson, 1999, p.801).

As the research question is receptive in nature, qualitative research techniques such as semi-structured interviewing, were the only way to gain a clear indication into the feelings of the participant and to gain access to their opinions, experiences and activities (Kvale, 2007). Interviews are the most beneficial chosen method for

qualitative research as they “reproduce a fundamental process through which knowledge about social world is constructed in normal human interaction” enabling a precise representation of data to be shown. (Legard, Keegan and Ward, 2003, p.138).

In order to gain rich and in-depth data, semi-structured in-depth interviews were used, using an interview schedule (see appendix 3) comprised of 16 open ended questions ranging from general, to background of education and training, to job satisfaction and to the positive and negative aspects surrounding caring. In-depth interviews combine structure and flexibility to the interviews (Ritchie and Lewis, 2007, p.141). Semi-structured interviews allowed the researcher to remain open to the interview, enabling them to take new directions based upon organisational context whilst discussing key themes highlighted in the literature review. The semi structured nature of the interviews allows them to remain interactive throughout and intends to generate naturally occurring data (Ritchie and Lewis, 2007, p. 168).

2.2 Materials

In order to answer the general research question, an interview schedule was compiled, consisting of 16 questions. The development of the questions led to the formation of themes, which were derived from both the literature review and research question. Academic books, peer review journal articles and official government reports were used to gather the literature review, with material discovered aiding the formation of the general research question.

2.3 Apparatus

A Philips Dictaphone was used to record each of the interviews after consent had been given from each participant. Following this the interviews were transcribed verbatim onto a word document and saved onto a password protected USB. Each of the transcriptions was then imported into Nvivo 10 which was the chosen Computer Assisted Qualitative Data Analysis (CAQDA) software. The software organised the data in preparation of analysis using codes and key themes. Thematic analysis using Nvivo software was chosen to analyse the data as this method is the most appropriate form of data analysis at finding patterns in responses and in portraying key themes.

2.4 Sample Participants

The sample for the research was comprised of eight Irish Caucasian participants, all of which were female. The gender distinction was chosen intentionally by the researcher, to avoid a gender comparison study taking place, and to gain a female perspective into caring that is defined as a woman's career. The participants were chosen based on their experience of working on a one to one basis with the sufferers of dementia. Each of participants required a minimum of three years care experience to take part in the study, with the ages of the participants ranging from early twenty's to late sixty's. Six of the participant's were care assistants working in a residential care setting and two were care assistants who cared for their patients in their own home. After the eighth interview the point of saturation was reached and interviews were ceased.

2.4.1 Sampling Methods

The participants for the study were assessed using convenience based sampling. This allowed the researcher to assess the participants with ease, using connections within the residential care setting and private home help organisations to gather possible participants (Ritchie and Lewis, 2003, p.81). A purposive or criterion based sampling method was then used to select the participants. The participants in the study were chosen as they had particular characteristics, such as, years of experience, gender, education and training and care setting which allowed for a detailed exploration and understanding of the central themes and puzzles (Ritchie and Lewis, 2003, p.78).

2.5 Procedure

The participants who took part in the study were contacted individually via telephone or via email by the researcher. On initial communication each participant was given a verbal or written explanation about the nature of the study and once an agreement was made to take part in the study, a time was arranged to conduct the research which suited both the participant and researcher. The setting of the interviews was chosen by each of the participants, in order for them to be in a comfortable and safe surrounding while conducting the interview. Seven of the interviews were conducted in the participant's work place, with one interview taking place in a coffee shop in the participant's local area.

Prior to conducting interviews each of the participants were given an

information letter (see appendix 1) which outlined the nature of the study, their right to withdrawal, and relevant contact information and outside support resources should the participants desire to avail of them. Each of the participants were asked to sign a consent form (see appendix 2) prior to taking part in the interview, to ensure that they were comfortable to take part in the study and had a full understanding of what the study entailed. The participants were informed that they were allowed to cease the interview at any time without question, and were reminded after the interview had ended that they had the right to withdraw any of their information at any time up until the research was published.

Interviews were recorded using a Philips Dictaphone once prior consent was given from the participants. The duration of the interviews ranged from 15 minutes to 37 minutes.

A variety of issues arose during the procedure of the interviews. These included certain participants being nervous, background noise, setting distractions, time constraints on the availability of the participants and interviews being interrupted.

One of the interviews in particular proved to have more interruptions than others, with the interview having to be paused on three separate occasions due to a telephone call and on two separate occasions due to colleagues entering the room. Although the interview was interrupted the researcher was still able to gain relative and informative information, which was very beneficial to the overall study.

Following the completion of the interviews, each interview was imported into a word document and transcribed verbatim, then processed through the software Nvivo 10 in order to further the analysis and then saved onto a password protected USB.

2.6 Data Analysis

The most appropriate form of analysis for data collection, in order to strengthen the research, was qualitative data-led thematic analysis. Thematic analysis was used as “a method for identifying, analysing and reporting patterns (themes) within data” (Braun and Clarke, 2006, p.79). QSR Nvivo 10 was the qualitative analysis program which was used to code and develop key themes which were highlighted within the research. Coding involved “identifying and recording one or more passages of text or other data items [...] exemplifying the same theoretical or descriptive idea” (Gibbs, 2007, p.38). A key part of the thematic analysis process was the researcher’s familiarisation of the data. Familiarisation with the raw data and cross-sectional labelling enabled the researcher to evolve and refine the themes (Ritchie and Lewis, 2003, p.220). It was necessary for the researcher to immerse themselves in the data, through the data collection phase, transcription phase and actively work with the data through the re-reading of the research. This allowed the researcher to divide the themes into sub-themes gaining a better perspective of the data findings and analysing the data further.

2.7 Ethical Consideration

Ethical issues were identified during the research and were adhered to using Dublin Business School's Ethical Guidelines for Research with Human Participants. A number of the ethical issues were discovered during the research which included confidentiality, informed consent, protection of participants, deception, debriefing and withdrawal.

Prior to conducting the interviews each of the participants were given an information letter (see appendix 1) addressing the nature and their involvement in the research, and were asked to sign a consent form (see appendix 2), stating their approval to take part in the study. Confidentiality was maintained throughout the research as none of the participants were mentioned directly, with any participant who revealed their name being given a pseudonym to protect their identity and privacy.

There was no risk to any of the participants during their involvement in the study, for example, the location to which the interviews were conducted was decided by the participant to ensure their comfort and safety while taking part in the interview.

The personal nature of the topic of dementia was taken into consideration while conducting the research, with the participants respect and dignity being maintained throughout the research. The participants were informed that if any question proved too difficult to answer they could refrain from answering and move on with the interview. They were also informed that they had the right to withdraw from the study at any time throughout the research without question. Following the

completion of the interviews, the participants and the researcher had a discussion about the issues that arose from the study creating an opportunity to debrief the sample in regards to the sensitive social issue of dementia, avoiding the participants becoming self damaged by their involvement with the research (Babbie, 2007, p.67). Finally the participants were given relevant contact information if they had any further question or queries that needed to be addressed.

3. RESULTS

3.1 Introduction

This section of the study will outline and analyse the findings of the research. A number of themes and sub-themes were found from the thematic analysis of the data, which allowed for further understanding of the research question “How does care work with the sufferers of dementia affect the care assistants?” Listed below are the main themes and sub-themes that emerged from the analysis:

1. Stress of Care Assistants
 - Causes of Stress
 - Coping Mechanisms for Stress
2. Work Burnout
3. Experiences of Aggression by Dementia Patients
4. Value in the Workplace
5. Staff Morale

3.2 Stress of Care Assistants

3.2.1 *Causes of stress*

Through the analysis of the research it was made apparent that stress was a key component in caring, with each of the participants experiencing stress within their role as carers. There were variations between the sample as to what in fact created

stress within their jobs, with the majority of participants portraying individualistic experiences. However there were some aspects that were seen as a common thread amongst the participants such as a lack of time, the deception of patients and staffing issues such as long shifts and conflicts within the work place.

“It’s very stressful when you can’t tell them the truth 100 per cent. It’s very frustrating to watch them at times because not all the time will you have an answer for them” (Bernie)

“Instead of having the time to sit with the patient and calm them the way you know is best for them, you have to rush, you have no choice in order to complete the duties of the day because there just isn’t enough time. It’s very overwhelming or it can be very overwhelming when a situation like this happens and you can’t do what you feel is best for the patient” (Aoife)

One participant’s experience of stress stood out from the rest of the sample with the trigger of frustration being completely directed at management and not the dementia patients themselves. Staff issues created major issues for this participant, creating a barrier between herself and the satisfaction of her job.

“When I’m stressed I become closed off and quiet and I get the feeling I’m getting angry in here and it would be a chore coming into work, you’d be awake at night thinking about coming into your job the next day. But I wouldn’t find it stressful with the residents I would be stressed with other members of staff” (Kim)

3.2.2 Coping Mechanisms for stress

The experiences of stress varied between the sample, highlighting different aspects of stress and coping mechanisms among the participants. All of the

participants felt that when leaving work after a shift, stress was definitely something that they would experience and that coping with it in some form was necessary to switch off from their role as a carer in order to step back into their own lives.

“Switch off when you go home” (Deirdre)

“When I get home I switch off and do my own thing” (Sarah)

One of the participants highlighted that experience is key to dealing with the stress that is created through caring stating that:

“Sometimes the only way to de-stress is on your journey home. In the beginning there are days when you’ll cry the whole way home from pure frustration and the over whelming feeling that you get when your not used to dealing with a dementia patient because you have to learn, although you're trained you have to learn how to not take it personally” (Aoife).

Having a supportive staff team was illustrated as a strong coping mechanism between three of the eight participants. Having someone to step in and assist or take over in certain circumstances was seen as paramount in dealing with stressful situations. It was discovered to be vital to the job to have someone available to talk to, who understands the circumstances.

“If you have a good team that works together someone can step in when you need to come back from it” (Deirdre)

3.3 Work Burnout

Burnout caused by caring for a dementia patient was something that was experienced by all of the participants. The same understanding of what creates burnout was shared by nearly all of the participants with the main components being lack of staff, long hours and staff not pulling their weight. All of the participants shared the same attitude towards the issue of burnout, answering the question without hesitation with each illustrating the negative opinion that surrounded the topic of burnout.

“It’s not always the patients that burn you out, it can be to do with the staff that don’t pull their weight and you’re the one that’s carrying everyone and it’s their job just as much as yours to take over” (Helen)

“The hours, the 12 hour shifts sometimes can be very tiring, like obviously in here its non stop bar your breaks, you can’t really just sit down and relax, and unless your sitting with a resident, it can burn you out physically” (Sarah)

“It’s a horrible thing to experience, it’s really not nice” (Kim)

One of the participants made a very influential point, one which really stuck with the researcher throughout the study, saying that there is literally no preparation that carers can take at times to ready themselves for the aspects of dementia care which will lead to overall burnout, stating:

“All the training, all the text you read, all the courses you do, you’re still a human underneath it all that information and all the education and training in the world doesn’t change that” (Aoife)

3.4 Aggression of Dementia Patients

The experience of aggression by dementia patients towards the carers was really quite apparent through each interview. All of the participants had experienced aggression by patients on one level or another. Although some experiences weren't as extreme as others, it was an issue among the sample that was very vivid in their explanation of their job. Each situation of aggression highlighted further to the researcher, the diversity of the illness of dementia itself and portrayed the illness as very individualistic to the patient, thus creating individual experiences for the carers.

“They don't know what's happening to their body and they don't know what's happening to their mind as well as not being able to recognize, walking up and not recognizing the place, they're getting annoyed and because they have the strength to say 'no I don't want to do that' or 'get away from me' no your not helping me dressing' they'll physically, they'll hurt you” (Kim)

One of the participants had the view that the aggressive nature in patients was something that was there before dementia set in stating that:

“I find that they're all different, some are aggressive and some are not, but I think it's in them all. It depends on if they were always that way, and when you talk to the family and you get to know them they tell you they were always that” (Helen).

“The aggression or the nature of the aggression is as individual with the patients as dementia is, to offer a solution it has to be tailored to the person” (Aoife).

3.5 Value in the Work Place

It was the common consensus between all of the participants that the level of respect that is shown to carers is so far below par, that there is no justification for the lack of value that the career of caring is given. None of the participants needed time to think of an answer when asked if they think that carers are looked down upon. Each of the participants was very passionate in their response, which portrayed a saddened aspect of the overall career. From interviewing the participants it is clear that the determination and love that they give to their patients is so extreme and true that it is very easy to understand that they are completely de-valued and stigmatised for their career path.

“I don’t feel any of us get the respect we deserve” (Samantha).

Two of the participants outlined the stereotypical attitudes that people have towards caring, confusing the career with that of a house keeper and stripping the profession of its status and value through ignorance and a failed interest to understand the true roles and responsibilities of a carers duties.

“People think your going in to scrub a strangers floor as opposed to making a big difference in their day and really helping them live on a more practical level, like even though house work is a part of my job there’s a big difference between caring for someone and caring for a house” (Hayley)

“You do get a stigma with it, but the stigma is only because of pure ignorance” (Kim)

“I think it’s underpaid because it's undervalued” (Aoife)

3.6 Staff Morale

The researcher found a significant difference between the attitudes of the participants towards their careers depending on whether they are surrounded by more positive or negative aspects. There was a direct correlation between the understanding of the carers to what in fact the positive and negative experiences of their jobs were and between the participants being made evident in their interpretations of their overall experiences.

The most significant cause of negative experiences within the job stemmed from major staff issues within residential care homes, which placed humongous pressure and strain on the care assistants and added unnecessary pressure to their day to day roles. This created a direct link to burnout, which was previously discussed, which diminished the satisfaction of caring and replaced it with a negative outlook. One participant even believed that staffing issues affected the care of the residents themselves stating that:

“There isn’t enough staff to tend to the residents. I believe the reason why the residents get frustrated 'ya' know sometimes, they could be having a bad day, but if they don’t calm down it’s because there isn’t enough time for a carer to spend time with them to help them calm or to bring them outside and to bring them for a walk” (Kim)

Although staffing issues created negative aspects within caring for the participants, it was evident from the sample that the illness of dementia itself created its own negativity, with one of the participants stating that:

“Sometimes it can be the patient themselves are just having a bad day, just like you or I could, and everything you try and know that has always worked with this patient, just won’t work. It’s these circumstances that make it difficult to separate what the negative actually is. It’s better for you to live in the patients’ world of dementia then expect the patient to live in your world” (Aoife).

Although dealing with negatives was a regular occurrence for the participants, it was shown that the career is surrounded by a variety of positive aspects that encompass the high level of satisfaction gained through caring. The career itself was viewed as more positive overall, with a direct correlation between six of the eight participants who shared the view that the positives outweigh the negatives. Even the two participants who viewed their job as more negative still found positives within their job, with all of the participants gaining a high level of satisfaction from caring, whether it was a patient smiling, saying thank you or just knowing that they helped someone who really needed it.

“The return is very high and it’s, like a lot of days you’d feel like a hero because what you’re doing to some people is so important that if someone tells you ‘thanks very much’ or ‘you did a great job’ or anything you feel great” (Hayley).

“At the end of the day whether the day has been good or bad you make a difference in someone’s life, it’s something worthwhile, something that’s necessary and something that contributes to someone else’s happiness” (Aoife)

The researcher found that by examining both the positives and negatives that it gave a clear perspective into the overall experience of caring, as by examining both the bad and good aspects of caring it enabled the researcher to interpret the sample’s overall view towards caring for the sufferers of dementia.

4. DISCUSSION

The aim of the research was to qualitatively explore the individual and shared experiences of the care assistants working with the sufferers of dementia. Five major themes were identified through thematic analysis which included stress of care assistants, work burnout, experiences of aggression by dementia patients, value in the workplace and staff moral. There was a direct connection between several of the themes with the findings having a direct correlation to previous research conducted in the area of dementia care. These connections will be analysed in this section of the study highlighting the similarities and disparities that exist between past and present research.

4.1 Stress of Care Assistants

As mentioned previously in section one of the research, stress can be defined as “the process that arises where work demands of various types and combinations exceed the persons capacity and capability to cope (Arnold, et al., 2010, p.435). The concept of stress can be viewed on a broad spectrum, however through the analysis of previous research and the current research findings, a narrower definition of stress was observed.

An express connection was identified between past research and the results of the current study. According to Berry (1998), role conflicts are a result of torn work relationships which can develop from possible work overload. Kim directly identified a shared opinion on the matter, expressing that stress could not only lead to

disagreements with co-workers but could also create a hesitancy to attend work. In some situations the pressure of caring increased not because of the patients themselves but due to the carer to patient ratio stretching her and fellow care assistants to the limit. This in turn led to a decrease in overall job satisfaction.

A direct correlation was found here between the participant's experiences of stress and work burnout. Although two separate themes were formed for each topic, major similarities were found between the two with stress being a main component of burnout within the work place. As stated above, staffing issues and conflicts created a certain extent of stress for carers. It was evident from the results that burnout was a direct product of staffing issues, with staff not pulling their weight and not taking over for another carer when necessary being the defining link to both burnout and stress. All of the participants experienced burnout in some form while dealing with the pressures of looking after a dementia patient, with long working hours being another key factor. This re-affirms the findings of a previous burnout study which found that the intense 14 hour shifts were a significant factor in burnout with care staff and found that 69 percent of the sample were suffering from a level of burnout (Trepel, 2007).

Although role conflicts remained to be a factor in both past and present research, coping mechanisms were illustrated to identify and deal with said stress within a stressful work environment. According to Arnold et al., (2010), support in the workplace has a positive impact on employees. A direct link between role conflict was portrayed in the literature review, examining the ways in which a breakdown in support systems in the workplace lead to friction, anger and disagreements between colleagues and increased the chances of stressors within the workplace (Arnold, et al.,

2010). The researcher was lead to believe that support within one's occupation is of vital importance to target stress and prevent it from reoccurring. This interpretation was strengthened in the findings of the study with the majority of the sample sharing the same view towards support systems in caring. Team work was seen as a vital aspect within caring for dementia patients in relation to stress management. Having a fellow carer to step in and relieve a carer for a few moments, allowing them to calm and relax themselves while handling a challenging situation, enabled the participants to continue with their work. Knowing that a supportive team stood behind them was a major factor in coping with stress, which the researcher believes is of paramount importance within care work.

It was evident to the researcher that the participants viewed their job as more than just a wage packet. The loyalty and respect that the carers had for their patients was extremely obvious through their outlook towards caring. Being trustworthy was portrayed as a serious factor in the relationship between the carer and patient. It was vital for the patients to have a level of trust for their carers in order for the correct care to be given to the patient. Being honest and open with their patients, although it created positives in the participant's caring roles, also created a certain extent of stress when being honest with a patient would only place them in a situation of uncertainty. Patients asking about deceased relatives or when they were going home, placed the carers in a situation where giving the truthful answer was not always best practice which for two of the participants in particular was seen as an unavoidable aspect of their job which leads to a feeling of deception and confusion. As dementia is a complex condition, dealing with day to day situations can be difficult and requires the carer to respond quickly and efficiently using the patient's background, their training

and their initiative to offer solutions. The study conducted by the Alzheimer's Society of Ireland identified that a lack of preparation to provide care was a direct trigger of stress which in turn had a resulting effect on overall job satisfaction (Zimmerman, et al., 2005). There is no concise way to prepare for caring of a dementia sufferer as the illness is so individualistic that there is no distinct understanding or interpretation of how to handle dementia patients. Patients, whether they are elated, sad, or acting in an aggressive nature, do not understand what is happening to their mind or body and something small can trigger a challenging episode that carers may not be prepared for or ready to handle. It is completely up to the carer to prepare themselves within seconds which once again identifies the intense work and dedication of the care assistants.

The relationship between burnout and stress arose here once again. One of the participants made a very influential point with regards to identifying the triggers of burnout within the workplace, stating it can be centred around the lack of preparation that is made possible for dementia care, which highlights that no amount of education, information or training can prepare you for certain instances that engulf caring for a sufferer of dementia.

4.2 Aggression of Dementia Patients

As previously mentioned in the literature review, behavioural disturbances have been ranked as one of the most distressing issues surrounding dementia care (Cummings, 2003, p.282). It was seen that all of the participants in this study had experienced some level of aggression by their patients while caring. The evidence of

aggression differed; although all participants had experienced aggressive behaviour the incidences were individualistic to the patient, therefore creating an individual experience for the carer. This corresponds to and re-affirms the result of the study conducted across the UK which identified the frequency and aggressive nature of the illness of dementia, with once again the majority of carers being subjected to aggression by patients within the workplace. 73 percent of the sample had experienced aggression by dementia patients, whether it was verbally or physically, with the result highlighting furthermore the distressing nature of dementia care (Alzheimer's Society, 2006).

Although similarities existed between the studies, a major difference was seen in terms of the willingness of the participants to talk about their experiences of aggression. The study conducted in the UK stressed the point that it is very rare for care assistants to record said aggressive experiences of their job, however in the current research each of the participants were very open about their experiences and did not hesitate or hide away when asked about the aggressive behaviour of patients. They were more than willing to explore and share their experience, even giving personal accounts of the challenges of aggression within the workplace.

A direct correlation was evident in regards to the understanding of aggressive tendencies within dementia patients. Aggression is not only a characteristic of personality but also a defining factor of dementia. Helen stated directly that dementia patients are aggressive due to the fact that they were that way inclined before the illness set in. According to the Alzheimer's Society (2013), the aggression of patients can not simply be defined due to their illness, but is distinguished through predisposed

mindsets, and is present prior to the development of the illness itself. Although aggressive behaviour can develop during the course of dementia, those who were always inclined to behave aggressively are more susceptible to exhibit aggressive behaviour (Alzheimer's Society, 2013).

4.3 Value in the Workplace

It was clear from both the research findings and previous studies that were undertaken in the field of caring, that caring is viewed and understood through a public perception, quite stereotypically. The career of caring is overrun by gender segregation and is viewed on the understanding of what is appropriate 'male' and 'female' work (Giddens, 2009, p.906). This common stereotype was made extremely apparent through the analysis of the interviews, two of which clearly outlined the public misinterpretation of the career with that of a house keeper's. Hayley went as far as pointing out that even though house work is an aspect of a carer's role, there is a lot more to caring for a person than caring for a house. This interpretation portrays further the typical female housewife image that is associated with caring, and also masks the level of dedication that is involved.

The lack of professionalisation surrounding caring is thoroughly highlighted throughout previous research accomplished in the area. Due to the unique nature of dementia care and the fact that it requires, even as a basic obligation, multi-disciplinary co-operation, it is evident that the need for status and power for itself is badly craved by the career (Miesen, 2004, p.414) & (Share and McElwee, 2005, p.42). Although it was not a determining factor in the participant's opinion of their

value within the workplace, the researcher's interpretation is that the stigma which exists around caring is brought upon by the lack of a professional title supplied to care assistants. This can also be mirrored in the lack of education and training on dementia care which is made accessible to care assistants. The researcher's findings suggest that an overhaul of both the education and professionalization of caring would lead to a reduction of the stigma attached to the career of dementia care, which as Kim highlighted is due to public ignorance. This in turn plays a significant role in the direct increase in a carer's value in the workplace.

Although both previous research and current research findings identify an under valuing of carers, discrepancies arose in the origin of said under valuation. Research conducted in Sweden on the value of care assistants, clearly illustrated the lack of value given to the care practitioners, not through public attitudes, but from the organisation they worked for. Powerlessness to change this issue was a common attitude felt by the participants, highlighting the diminished attitudes of the sample (Kristiansen, et al, 2006). A disparity between the current research findings exists, as the overall sample believed that the lack of respect shown to care assistants was created from the outset, through the eyes of the public, identifying further the ignorance and lack of knowledge of what in fact dementia care entails.

4.4 Limitations

Various limitations of the study arose while conducting the research. The principle limitation was the significantly small scale sample that was used in undertaking the research. To get a clearer indication of the overall experiences of care

assistants, a wider sample would be needed and would result in a more in-depth analysis of the different aspects of caring. Time constraints were another factor that may have hindered the research findings. Qualitative methods are a lengthy process, and with a variation in the availability of the participants, this could have led to a gap in the research.

Another limitation of the study arose in connection with the lack of previous research being conducted in the area of dementia care, from a care assistant perspective. The vast majority of research that was available in the area was conducted on a family carer's perspective, with attention lacking on the care assistants outside of family ties.

In retrospect of the findings, the researcher would not have used a sample from the same cultural backgrounds. The participants in the study were all Irish Caucasian females. This disallowed the researcher to gain a deeper understanding of the care assistant's experiences, as it failed to look at a variety of ethnic and cultural backgrounds where a diversity of experiences could have been found.

4.5 Suggestions for Future Research

Although a small scale sample was successful in conducting the research, a larger sample would be recommended for further research in order to identify a variety of aspects surrounding dementia care, leading to a multiplicity of experiences becoming identified and furthering the knowledge in the area. The lack of research in the area was a major drawback for the study. It was noted by the researcher that any

future developments in dementia care research would strengthen the field, gaining deeper and clearer perspectives into both the overall experiences of care assistants and also into the illness itself.

4.6 Conclusion

The aim of the study was to answer the general research question “how does care work with dementia sufferers affect the care assistants” and set out with the objective to explore the experiences of the care assistants working with the sufferers of dementia. Dementia is an invidious progressive condition for which there is currently no cure or clinical solution (Cahill, et al., 2012). Through the analysis of the findings in the study and in those of previous studies that have been conducted, the lack of knowledge about dementia care is extremely apparent throughout society as a whole and also throughout the health service profession. Developing a clear answer to the research question proved quite difficult for the researcher as the experiences of the care assistants, although highlighting some similarities, also had major variations which were still seen to be evident in the area and also due to the individualistic nature of the illness of dementia itself. However although variations existed there was seen to be a correlation in certain attitudes of the carers towards their value, certain aspects of stress and their overall experience of burnout.

The stigma attached to caring presented itself in both past and current research, illustrating it as a major issue for care assistants. The public perspective of carers was made evident through the analysis of the study giving way to an ignorant demeanour and a lack of interest in the area of dementia care with the public failing to

give recognition to the complex profession that is dementia care.

The overall findings of the study made the researcher conclude that there is no direct answer for the ways in which carers are affected through dementia care. Both positives and negatives were made apparent by the participants, illustrating that there is no direct definition of the effects, but rather that it is engulfed by the diverse nature of the carer and the patient themselves.

Although the findings did not result in a distinctive answer to the general research question, the research will still uphold to the objective to contribute to the body of knowledge surrounding dementia care and the effects it creates for the care assistants working to assist and support people on their journey through the disease trajectory.

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APPENDENCIES

Appendix 1: Information Letter



My name is Aislinn Dunne and I am conducting research for my third year final research project. The aim of the research is to explore the experiences of the care assistants working with the sufferers of dementia. The research will look at both the individual and shared experiences of the care assistants.

The research will be carried out using interviews. The interview will consist of 12-16 questions and will take place over roughly 40 minutes. To gain a deep understanding of the experiences of working with a dementia sufferer between 8-10 interviews will be conducted.

Participation in the study is completely voluntary and no one is obliged to take part. If any questions in the interviews create difficult feelings, the question does not have to be answered, with the rest of the interview still being able to be continued.

All participants have the right to withdrawal from the study at any time and will remain confidential throughout the entire study. If any participant wishes to for their interview to be removed from the study they will be accommodated up until the research is published. Any piece of information that participants share such as interview and associated documentation will be securely stored using a password protected USB.

For further information or to answer any queries contact:

Aislinn Dunne (Aislinn.dunne8@gmail.com) Dr.Niall Hanlon (niall.hanlon@dbs.ie)

If affected by any aspect of the study and seek further advice contact:

The Samaritans: <http://www.samaritans.org/your-community/samaritans-work-ireland>

HIAUQ : <http://www.hiqa.ie/>

HSE: <http://www.hse.ie/eng/>

Appendix 2: Consent Form



To Explore the Experiences of the Care Assistants working with the Sufferers of Dementia.

My name is Aislinn Dunne and I am conducting research that explores the shared or individual experiences of the care assistants working with the sufferers of dementia.

You are invited to take part in this study and participation involves a recorded interview using a Dictaphone that will take roughly 40 minutes.

Participation is completely voluntary and so you are not obliged to take part. If you do take part and any of the questions do raise difficult feelings, you do not have to answer that question, and/or continue with the interview.

Participation is confidential. If, after the interview has been completed, you wish to have your interview removed from the study this can be accommodated up until the research study is published. Each participant will remain completely anonymous throughout the entire study, with each interviewee being assigned a pseudonym.

The interview, and all associated documentation, will be securely stored and stored on a password protected computer.

It is important that you understand that by completing and submitting the interview that you are consenting to participate in the study.

Should you require any further information about the research, please contact
AISLINN DUNNE (aislinn.dunne8@gmail.com) Dr. NIALL HANLON
(niall.hanlon@dbs.ie)

Thank you for participating in this study.

Participant Signature: _____ Date: _____

Appendix 3: Interview Schedule

Warm up: Hi how are you?

I just like to thank you for taking part in the study today. The aim here is to look into your experiences of caring for a sufferer of dementia and to gain a clear understanding in what is involved in the caring from the professional side both physically and mentally. I would like to remind you that you have the right to withdraw from the study at any time throughout the interview, and if any question is too difficult to answer we can just move on to the following questions.

1. Can you tell me a bit about yourself?
2. What made you decide to choose a career as a professional carer?
3. What education/ training did you need in order to become a carer?
4. What are your roles and responsibilities as a professional carer?
5. What level of satisfaction is gained from your job?
6. What benefits are created in this line of work?
7. What negative aspects are there surrounding caring for a dementia patient?
8. In what ways can dealing with a patient become overpowering or stressful?
9. Under what circumstances would you experience possible work burnout or a loss in job satisfaction?
10. There are obvious emotional aspects involved in caring for someone with dementia. In what ways would you ever find it difficult to switch off from your role as a carer, perhaps bring your work home with you?

11. Could you describe a time where you have felt unsafe dealing with a patient?
12. Could you describe a time where a patient has become aggressive with you?
13. Like every job stress is a factor, how do you deal and manage your stress within your job?
14. Do you feel carers receive the respect they deserve? Do you ever feel that it is a career that can be looked down upon?
15. Would you say looking at you career as a whole that there are more positive or negative aspects surrounding caring for a dementia patient?
16. Based on your professional and practical experience, would you recommend any changes or additions to the services for dementia sufferers?

I would like to thank you again for taking part in the study. Your involvement has been extremely beneficial and I really appreciate taking time out of your day to take part. Once again I would like to remind you that you will remain completely anonymous throughout the study, and have the right to withdraw any of your involvement and shared information up until the research is published.