

“SIDELINED”

**Family Caregiver’s Experience of the
Emergency Department : Insights from family caregivers of people with
Alzheimer’s Disease**

by

Sandra Roberta Ridley

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Abstract

Older patients with a cognitive deficit, such as seen in Alzheimer's Disease (AD), have not been extensively researched in ED. Often patients with AD are accompanied by a familiar person such as a family caregiver when they present to an acute care facility. Literature has shown that family caregivers' have reported dissatisfaction with interaction with healthcare professionals in inpatient settings. There is a paucity of research on the experiences family caregivers have in ED. This study explored the experiences of family caregivers of people with Alzheimer's Disease in the ED of a regional hospital in New Zealand. A Hermeneutic phenomenology method was used to bring meaning to the lived experience of family caregivers in the ED. Ricouers Interpretation theory was used to analyse and interpret the data. Six family caregivers were interviewed, using semi-structured interviews, to explore and give meaning to their experience. Findings revealed family caregivers were 'sidelined'; felt invisible, ignored and abandoned by the healthcare professionals in ED. There appeared to be little understanding about dementia symptoms, or the needs of caregivers of people with AD. The experience was distressing for participants who felt they were not able to relay information about their loved one that was pertinent to their health and presenting symptoms. Health Professionals tended to speak directly to their loved ones and not with the participants. Consequently there was a risk of misinformation and poor communication driving treatment decisions for these patients. Participants reported poor information giving and family caregivers were left for long periods of time with no contact, and no support. Despite this, caregivers justified and excused the actions of healthcare professionals. They became passive recipients of process and procedures that were not adequately explained.

Keywords: Family caregiver; Emergency Department; Alzheimer's Disease; Phenomenology.

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Glossary of Terms

Alzheimer's Disease:

Alzheimer's disease is a degenerative cerebral disease of unknown etiology. It has characteristic neuropathological and neurochemical features. Usually insidious at onset it develops slowly but steadily over a period of years. The incidence is higher in later life but it can start in middle life or occasionally earlier. With onset before the age of 65yrs-70yrs, there is the likelihood of a family history of a similar dementia, a more rapid course, and prominence of features. In later onset progression tends to be slower and to be characterized by more general impairment of higher cortical functions. (World Health Organisation, ICD-10, Dementia in Alzheimer's disease).

Emergency Department:

A section of (a hospital) that is staffed and equipped to provide rapid and varied emergency care, especially for those who are stricken with sudden and acute illness or who are the victims of severe trauma (Mosby, 2002).

District Health Board:

District Health Boards (DHBs) are responsible for providing, or funding the provision of, health and disability services in their district. There are 20 DHBs in New Zealand and they have existed since 1 January 2001 when the New Zealand Public Health and Disability Act 2000 came into force (Ministry of Health NZ, 2009).

Family caregiver:

A family member who cares for another member of their family in the community. Most of the caring for people with dementia is done by women, most often wives, then daughters and daughters-in-law (Perkins, 2006).

Registered Nurse: Registered nurses utilise nursing knowledge and complex nursing judgment to assess health needs and provide care, and to advise and support people to manage their health. They practise independently and in collaboration with other health professionals, perform general nursing functions and delegate to and direct enrolled nurses, healthcare assistants and others. They provide comprehensive

assessments to develop, implement, and evaluate an integrated plan of health care, and provide interventions that require substantial scientific and professional knowledge, skills and clinical decision making. This occurs in a range of settings in partnership with individuals, families, whanau and communities. Registered nurses may practise in a variety of clinical contexts depending on their educational preparation and practice experience (Nursing Council of New Zealand, 2008)

Chapter 1 Introduction

1.1 Background

Healthcare for the elderly is focused on preventative care and ageing in place in New Zealand. Ageing in place is a term that describes maintaining independence, allowing a person to live in their own home for as long as possible (Keeling, 1999). Many elderly people are able to remain in their own homes with services to support their independence. Among the numbers of elderly residing in the community are those diagnosed with dementia, this number in New Zealand (NZ) is approximately 40,746 and is expected to increase to approximately 74,821 by the year 2026. (Dementia Economic Impact Report, 2008). Reducing the burgeoning cost of healthcare is at the centre of initiatives to manage the demand an increasing number of older people will place on healthcare systems (Ministry of Health, 2002; NZ Dementia Strategy 2010-2015; NZ Dementia Manifesto, 2008; NZ Dementia Economic Impact Report, 2008). The cost of dementia in dollar terms in 2008 was \$712.9 million, of this total \$435.7 million was for health system expenses, 61.1% of the total expenditure (NZ Dementia Economic Impact Report, 2008). This cost is in stark contrast with the amount of money spent on dementia research which is estimated at around \$2.9 million, equating to approximately \$75 per person with dementia, per annum. This is considerably lower than in Australia and other Organisation for Economic Co-operation and Development (OECD) countries (Dementia Economic Impact Report, 2008).

Alongside the focus on cost containment is an increasing interest in the role informal caregivers play in maintaining people at home in the community. As part of this interest the needs of these caregivers have been researched extensively, and there is strong evidence to suggest they are not being met (Jorgensen, Parsons, Jacobs, Arksey, 2010; Bookman and Harrington, 2007; Redley, 1996; Pytel, Fielden, Meyer, Albert, 2009).

Emergency departments (EDs) are the receiving point for either admission into the hospital, or treatment and discharge, and information and communication are vital to prevent confusion, frustration, and misunderstanding. Consent for treatment is given in ED thus in the case of

impaired capacity it is essential that, where possible, informal or family caregiver opinion is sought prior to decision making around options for further treatment.

Capacity is: *"...the ability to receive, process and understand information, the ability to deliberate, the ability to make choices, and the ability to communicate those preferences"* (Larkin, Marco & Abbott, 2001, p282).

When a person has a cognitive deficit, such as seen in Alzheimer's Disease, (AD) the family caregiver is often the person who has the most knowledge of recent and past events. They are aware of the person's health status, allergies, and medications, and can relay this information to health professionals (Bookman & Harrington, 2007). Much of the research on communication in ED does not specifically identify family caregivers as the focus, and there is a gap in research from a family caregiver perspective specific to their experience in ED (Parke, Beath, Slater, & Clarke, 2011).

1.2 Researcher background

I am a Registered General and Obstetric Nurse with a career spanning over 30 years, predominantly in the practice of chronic disease management, within both hospital and community settings. I have always endeavoured to support and learn from the family, friends, and significant others involved in the lives of patients I have nursed. It is this experience that has shaped my interest in the role of the family caregiver.

The catalyst for undertaking this study was a request I received from the Alzheimer's Society to speak to spouses and caregivers of people with Alzheimer's Disease (AD), at a caregiver support meeting. The topic of interest was hospitalisation, and discharge planning for their loved ones. During question and answer time I became aware of the extent of unmet needs these caregivers had in the hospital setting. I was particularly interested in the experience they had while in ED. It appeared there was a significant need for improvements in communication between staff in the ED and family caregivers of people with AD.

1.3 Research aims and objectives

The aim of this study was to give meaning to and interpret the experiences of family caregivers of people with AD in ED, at a regional hospital in New Zealand. The objectives were to:

- Explore the experience of taking a loved one with dementia to ED
- Interpret and describe this experience
- Provide evidential insight to assist practice development in this setting that is directed toward the inclusion of family caregivers in health assessment and decision making for the person with AD.

1.4 Overview of Thesis

Chapter One: Introduction

This chapter introduces the topic of my study and the background. The research question is introduced along with the objectives.

Chapter Two: Literature Review

Literature was examined to ascertain what is known about this topic within Chapter Two. This identified gaps in research and provided the rationale for undertaking this study.

Chapter Three: Methodology

This chapter describes in detail the study design, methodology, and methods used to conduct this study. The analysis method is comprehensively explained and an audit trial described.

Chapter Four: Study Results

Chapter Four presents the findings of the study.

Chapter Five: Discussion

In Chapter Five discussion relating to the findings is presented, along with information sourced from a second literature search. The limitations of this study are also presented, along with recommendations for further research, and a conclusion.

1.5 Summary

I have introduced the reader to the thesis study in this chapter. Relevance of the study has been discussed along with my interest in this area of healthcare. The study objectives have been identified and an overview of the thesis structure is provided. Background literature is covered in the following chapter.

Chapter 2 Literature Review

2.1 Introduction

When reflecting on the responses from my presentation to the AD group caregivers', poor communication was one of the key issues discussed. In preparation for this study I examined the subject of communication in depth. Barriers to effective communication (as seen in AD) are discussed to set the scene, and illustrate the importance of family caregiver presence in the acute healthcare setting. Interventions to reduce the adverse outcomes of caring are discussed along with caregiver interaction with healthcare professionals and the issues that arise from this. The New Zealand context is explored from a governmental and non-governmental perspective to identify the way forward for caregivers of people with AD. ED use of triage is examined and critiqued in relation to older people with cognitive decline in ED. The aim of this review was to outline gaps in the research leading to the thesis study undertaken.

2.2 Search Strategy

I conducted an initial search with the Victoria University of Wellington (Nursing) Subject Librarian. Databases explored included Pubmed, PsycINFO, the Cumulative Index to Nursing and Allied Health (CINAHL). NZ Government sites were also searched for policy documents. Keywords used for search were: family; caregiver; caregiver; Alzheimer's Disease; dementia; communication; Emergency Department; ED; Casualty; Trauma centre; A&E; Triage; New Zealand. This search was filtered to publications between 1980 and 2011, and only those with full text to provide online access to material. Searching of the literature continued throughout the data analysis period and further search terms were identified following data analysis, such as 'older people', 'elderly' and 'aged'. This later literature is addressed in the discussion chapter.

2.3 Communication

Communication is "the activity or process of expressing ideas and feelings or of giving people information" (Oxford Advanced Learners Dictionary, 2010). Northouse and Northouse (1985) define communication as "the

process of sharing information through a set of common rules” (p.3). They further define communication as a set of contexts. Communication contexts are explained as:

- intrapersonal (the inner voice)
- interpersonal (between two or three people)
- small group (meetings, social gatherings)
- organisational (flow of communication within an organisation)
- public communication (public announcements, large group presentation)
- mass communication (media releases, Internet)

(Northouse & Northouse, 1985, p.5) Communication in health has been a topic of research for the past 30 years. The topic appeared in the 1970s and has grown in significance with new issues such as the ageing population, and the increasing cost of healthcare throughout the world (Wright, Sparks & O’Hair, 2008). Northouse and Northouse (1985) developed the *Developmental Model of Health Communication*. The model is depicted in Figure 1 (p.7.). It describes a process of communication specific to the health environment. The process of health communication has three major factors: *participants, health transactions, and health care contexts*.

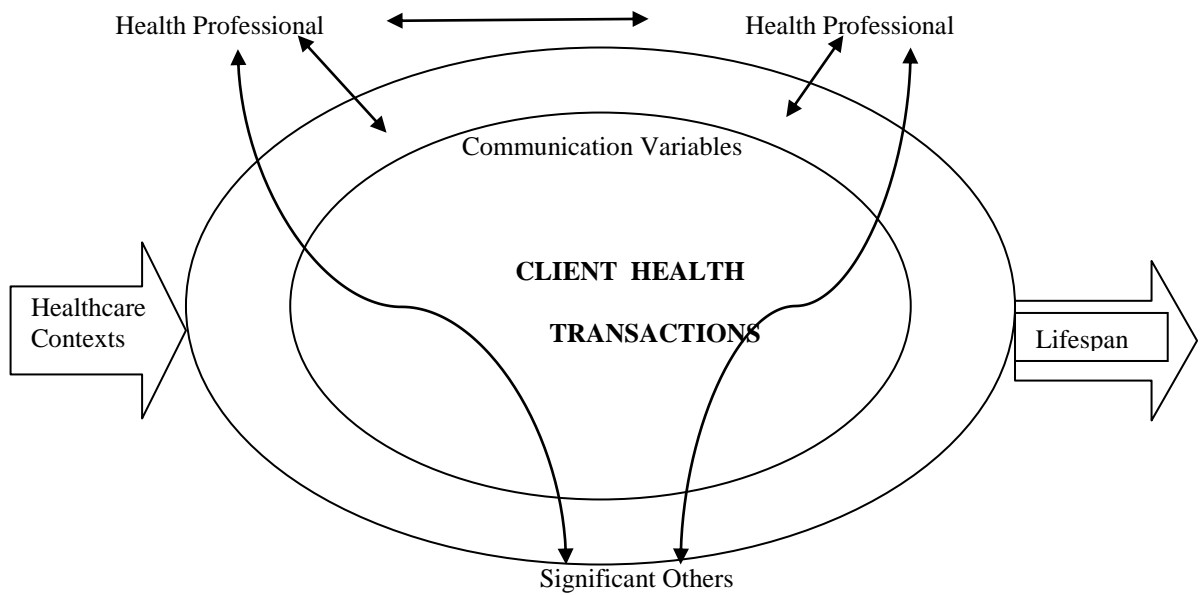


Figure 1. The Developmental Model of Health Communication adapted from Northouse, P.G., & Northouse, L.L.(1985) *Health Communication: a handbook for health professionals*. Englewood Cliffs. New Jersey: Prentice-Hall, Inc.

The model outlines communication between health professionals and the client and their family. This model acknowledges communication between health professionals and between the client and their family in relation to health transactions. The healthcare context is divided into healthcare transactions or episodes of communication related to the physical and psychosocial wellbeing of the patient. These transactions can be between any of the participants and may be randomly set so are therefore defined as *communication variables*.

Participants are health professionals, clients/patients and significant others. This model acknowledges the impact of family and significant others in the communication process. This acknowledgement differentiates it from other models and makes it applicable when considering communication in the ED environment as many older adults are accompanied by family members or support person/s when they present with a health crisis. A *health*

professional is defined as any individual who is trained and provides health services to others. *Patients* are the individuals who receive health services and *context* is the setting where health services are received. Context is important when thinking about health communication, for example communication in an outpatient clinic or in consultation rooms, may differ from communication in the ED. The amount of noise and interruptions may not be significant in the former setting but could be a barrier to effective communication in the latter. Environment becomes particularly significant when communicating with a person with dementia as distraction and over stimulation will influence quality of communication (Adams & Gardiner, 2005).

Health transactions are the health-related interactions that occur between participants. Health transactions can occur between any combinations of participants, including significant others (Northouse & Northouse, 1985). The model adheres to the belief that communication is an interactional process based on the beliefs and feelings brought into the interaction by all individuals involved. In busy healthcare practices healthcare interactions are time limited, increasing the importance of communication that is of value to the person, their family and significant other/s. Research focused on caregiver needs from healthcare professionals often highlights the need for more time spent on communication and psychosocial support (Chambers, Ryan & Connor, 2001; Downs, et al, 2006; Walker & Dewar, 2001).

2.4 Communication with Alzheimer's patients

Cognitive decline as seen in AD can affect communication by causing a lack of concentration and the inability to sustain a conversation in the early stages, and progress to complete inability to speak or take part in conversation in the latter stages of the disease, where there is an inability to initiate conversation (Haak, 2003; Lubinski, 2010; Wright et al 2008).

Ripich, Wykle, and Nyles (1995) studied the effect of a formal caregiver communication training program named the FOCUSED communication skills program. FOCUSED is an acronym for: *f*ace to face, *o*rientation, *c*ontinuity, *u*nsticking, *s*tructure, *e*xchanges and *d*irect. Post program improvements were seen in both knowledge and communication satisfaction from caregivers. Caregivers also described a greater feeling of

control when communicating with their patients. They were less frustrated and more confident and so tended to communicate more. Part of the program is devoted to identification and description of stages of communication decline (Table 1).

Table 1: Stages of Communication Decline in Alzheimer’s Disease.

Ripich, D., Wylke, M., Niles, S. (1995). Alzheimer’s Disease Caregivers: The FOCUSED Program. *Geriatric Nursing*, 16(1), 15-19.

<i>Stage I</i>	<ol style="list-style-type: none"> 1. Cannot find words or names 2. Long pauses and slower responses 3. Digress from topic 4. May self-correct or apologise for communication failures
<i>Stage II</i>	<ol style="list-style-type: none"> 1. May ask you to repeat several times before they understand you 2. Cannot follow simple directions, unless coached 3. Loss of factual knowledge 4. Cannot recall familiar words or names
<i>Stage III</i>	<ol style="list-style-type: none"> 1. Naming seriously impaired, so vocabulary is very limited 2. Cannot understand simple words 3. May talk or babble excessively but without meaning 4. May withdraw and not speak at all

Family caregivers have also been given communication training and the effectiveness of this training assessed. In a study by Roque, Ortiz, Araújo and Bertolucci (2009) the effectiveness of a training program for family caregivers of patients with moderate AD revealed effectiveness in changing the communication behaviour of caregivers. The program was provided by a speech-language pathologist and analysis of results of the post intervention questionnaire and video observation was completed by specially prepared speech-language pathology students. Despite 34 caregivers being identified as meeting the study criteria, 15 declined to participate. The researchers hypothesized this may be due to lack of awareness of communication difficulties, communication being low priority in relation to other problems, and the study being another thing to be completed. (Roque, et al, 2009).

Acton, Yauk, Hopkins, and Mayhew (2007) researched the use of Kitwood's (1988) collaborative social communication training compared to usual communication on residents in a residential care facility in the United States of America. Ten people with dementia were engaged in conversations with two advanced practice nurses (APNs). One APN was experienced in dementia care but had not received any training in Kitwood's strategies (interview 1), the other APN was trained in Kitwood's strategies (interview 2). Results indicated that although there was no increase in the total number of words participants used from interview 1 to interview 2, the participants used more words per topic in interview 2 than they did in interview 1 (527 words for interview 1 and 788 words for interview 2). Also the percentage of topics introduced by participants increased in interview 2 and the total number of topics needed to sustain a 15 minute conversation decreased from interview 1 to interview 2. This indicated participants were able to sustain conversation about each topic longer in interview 2. Results confirmed that staff trained in collaborative communication strategies were more effective in their communication with patients with AD (Acton et al.).

2.5 Caregiver burden

Caregiver stress and burnout is recognised as significant and has been widely discussed in literature. Brown and Kleist (1999) reviewed current literature on AD and the family to inform family counsellors. Findings reveal the extent of stress experienced by family caregivers and the resulting effects on other systems. They showed a lack of support services and communication about existing services. They also revealed the effects of caregiver grief and the need for family counsellor intervention.

Yilmaz, Turan and Gundogar (2009) investigated the factors related to burnout in the family caregivers of AD. Results indicated that the emotional exhaustion of the caregiver increases as the functional ability of the care recipient decreases. The depression level of the caregiver was correlated with emotional exhaustion but it was not a determinant of exhaustion. The depression level of the care recipient led to an increased depersonalisation by the caregiver. This may indicate burnout is a factor causing caregivers to relinquish care and place the care recipient in a residential care facility.

Early recognition of psychiatric symptoms in family caregivers can be difficult. Ulstein, Wyller and Engdal (2006) compare scores on the Relative

Stress Scale (RSS) with those on the General Health Questionnaire (GHQ) and the Geriatric Depression Scale (GDS) and establish a cut-off score for RSS in order to distinguish caregivers with symptoms of psychiatric disorders from those without. This study serves to validate testing methods to establish caregiver stress and burden level.

Along with the risk of psychological damage from the burden of caregiving there is a physical toll to pay for caregivers. Kiecolt-Glaser et al (1987) studied the effect of a long term or chronic stressor on caregivers. Results indicated caregivers had more stressors and a poorer immune function than well matched age peers. This was particularly significant when the caregiver is a spouse or older adult with age-related decrement in immune function.

2.6 Interventional Studies

Most studies carried out to gauge the effectiveness of interventions to reduce caregiver stress and burden have been community-based. Ulstein, Sandrik and Wyller (2007) conducted a randomised controlled psychosocial intervention study among family caregivers of people with dementia to gauge the effect on caregivers and patients. Caregivers of the intervention group were educated about dementia and in six group meetings taught how to use structured problem-solving. The control group received treatment as usual. The effect on patients was measured with the Neuropsychiatric Inventory and on caregivers with the Relatives Stress Scale (RSS). The burden measured by the RSS increased in both groups; however, more caregivers of the control group converted from a low-burden group to a medium or high-burden group after 4.5 months. They concluded that there was no real benefit from a standard intervention, rather this indicated interventions need to be individually tailored to meet each caregiver need.

Schulz et al (2002) reviewed all intervention studies that reported dementia caregiver outcomes from 1996. Their goal was to focus on issues of clinical significance in caregiver intervention research, to move the field toward a greater emphasis on achieving reliable and clinically meaningful outcomes. They concluded there were only a small amount of studies that achieved clinically meaningful outcomes. The studies have “increasingly shown promise of affecting important public health outcomes in areas such as service utilization, including delayed institutionalization, psychiatric

symptomatology, including the successful treatment of major and minor depression; and providing services that are highly valued by caregivers.” (Schultz et al., 2002, p 589)

Sparse clinically significant caregiver interventions may lead to early institutionalisation of people with dementia as caregivers struggle to access services that meet their needs. Bruno (2006) studied the lived experience of caregivers when they have relinquished full-time care. The main discovery was that caregivers from a non-English speaking background had compromised life satisfaction and poor psychological health. “The practice implications include the identification of ‘at risk’ caregiver groups and the need for appropriate supports for dementia caregivers at all stages of the caring process”. (Bruno, 2006, p188).

Interventions designed to delay institutionalisation have been utilised. Dröes, Breebart, Meiland, Van Tilburg, and Mellenbergh (2004) studied the effect of Meeting Centres Support Programs on feelings of competence of family caregivers and delay of institutionalisation of people with dementia. Results indicated those enrolled in the program participated for a longer period of time before institutionalisation, in comparison to the control group who were enrolled in a day-care program. Further studies on the value of meeting centres for caregivers of people with dementia are recommended to enrich these findings.

In a study by Marriott, Donaldson, Tarrier and Burns (2000), the effect of a cognitive behavioural family intervention in reducing the burden of care in caregivers of people with AD was explored. A prospective single blind randomized controlled trial was conducted, with a three-month follow-up, in which the experimental group received intervention and was compared with two control groups. Results showed significant reductions in distress and depression in the intervention group compared with the control groups at post-treatment and follow-up.

2.7 Primary Care Perspective

There is evidence of poor awareness of dementia guidelines among General Practitioners (GPs) in the United Kingdom, and confusion around

their role in managing home care for community dwelling patients with dementia (Shoenmakers, Buntinx, and Delepeliere, 2009). GPs report barriers to more comprehensive management, among these are the lack of interdisciplinary teams, poor interaction with social services, and difficulty accessing specialist support (Hinton, et al, 2007). Time constraints and reimbursement issues contribute to the inability to support caregivers and their loved ones adequately in the community (Hinton et al., 2007).

Glasser and Miller (1998) studied the medical encounter from the perspective of both the GP, and the caregiver of a person with dementia, and concluded physicians are not attending to caregivers concerns and contributions adequately. Overall, physicians tended to evaluate their efforts more highly than did caregivers. Caregivers seemed to want and expect more input from the physician regarding management and psychosocial issues. Caregivers value GPs who display effective communication skills and good interpersonal attributes. They expect to be listened to and have their concerns acknowledged. Timely referral to other services is also valued (Downs et al., 2006).

Issues with caregivers' rights have resulted in legislation being passed in the UK to support family caregivers. The Caregivers Act 1995 formally recognises the caregivers' role and sets out objectives in the Practice Guideline accompanying the Act. Seddon and Robinson (2001) studied how the Caregivers Act was being interpreted and implemented in practice. Their results indicated both caregivers and health professionals have limited knowledge of the Act and it has had minimal impact at practice level.

2.8 Acute care perspectives

Family caregivers have been labelled a *shadow workforce* by Bookman and Harrington (2007). They are challenged by fragmented and under resourced healthcare services. In this context they become case managers for their relatives, communicating between the various services and health professionals to provide the best possible care in an overburdened public health system (Bookman & Harrington). Often they are the only people aware of what medications their loved one is on and what co-morbidities they have. In the early stages of dementia people can give very convincing answers to medical questions but the answers are often faulty. In this

context the health professional is reliant on the family to corroborate and/or provide accurate information on behalf of the person with dementia (Bookman & Harrington). In the acute health care arena studies highlight the difficulties informal caregivers have accessing information, and interacting with health professionals (Chambers, et al., 2001; Laitinen and Isola, 1996; Walker and Dewar, 2001).

Caregivers support their care recipients when they become physically unwell and are admitted to hospital. May, Ellis-Hill and Payne (2001) explore the relationship between informal caregivers of older people, and health care workers within the context of a hospital ward. Communication between family caregivers and professional staff (registered nurses, occupational therapists, physiotherapists, dietitians, housekeepers, nursing auxiliaries and ambulance staff) was videotaped and analysed using conversational analysis. Analysis revealed that a central aspect of the way the relationship between informal caregivers and healthcare workers is framed is via information and access to information. Ownership of information by healthcare professionals (both clinical and institutional) plays a part in power relationships that can readily form in this situation (May et al., 2001).

Using semi-structured focus interviews to explore the emotional support needs and coping strategies of family caregivers, Chambers et al., (2001) found that caregivers requested they receive more hands-on training, and education, to support their caring role prior to the discharge of the care recipient. The caregivers felt the onus was on the them to make contact with formal services. They also felt financial stress was overlooked in their care giving role leading to lack of advice about financial entitlements they may qualify for. The authors noted in their conclusion that hospital nurses are in an ideal position to meet caregivers, provide support, offer advice and encourage participation and involvement in the decision making process.

Caregiver involvement in the hospital setting was investigated by Walker and Dewar (2001) who identified four markers of satisfactory involvement. These are: "feeling that information is shared; feeling included in decision making; feeling that there is someone you can contact when you need to; and feeling the service is responsive to your needs." (Walker & Dewar, 2001, p.329).

Caregivers were dissatisfied with lack of involvement highlighting two sources of difficulty. These were the hospital process and systems and the relationship between nurses and caregivers. Walker and Dewar (2001) argued that health practitioners must notice and challenge these barriers to effect positive improvement in caregiver involvement.

In a study by Laitinen and Isola (1996) factors enabling and limiting participation of caregivers in the hospital setting were explored from a caregiver perspective. They found that communication between caregivers and nursing staff played a significant part in enabling or limiting the caregivers' participation in care on the ward. If caregivers felt welcome, respected, and of use they were more likely to participate, conversely, if they perceived they were not respected they were reluctant to offer information and participate in care. Thus they made this conclusion:

“If the goal of family involvement is improvement of quality of care, then nurses' early cooperation with family members is likely to reinforce the relatives' feelings that their efforts are valued and welcomed and can contribute to the quality of elderly person's life” (Schwartz & Vogel 1990 cited in Laitinen and Isola 1996,p 945).

There are tensions evident in relations between caregiver and healthcare staff. The difference between caring for a loved one in the domestic environment and watching staff care for them in a hospital setting often causes frustrations on both sides. It is difficult for staff to fully involve an expert caregiver in the ward environment where the caregiver's only concern is for the care of their loved one, but the nurse is caring for more than one patient and even the physical space allocated to the patient is insufficient to allow more than two people comfortably around the patient at once (Allen, 2000).

2.9 The New Zealand context

There are approximately 420,000 people identified as informal caregivers in New Zealand of this group 38% are 45-64 years old, 31% are 30-44 years

old and 12% are aged 65 years old and over (Ministry of Social Development (MSD), 2008).

In late 2007 the sitting Labour Government announced they were to commence working on the New Zealand Caregivers Strategy to acknowledge the growing number of family caregivers in the community. The Minister of Social Development (MSD) launched this strategy in April 2008. Recommendations from the strategy form the basis of a five year plan. The strategy has been developed in collaboration with Caregivers New Zealand, the New Zealand Caregivers Alliance and other government agencies (MSD, 2008).

The NZ Carers Strategy (MSD, 2008) covers all informal caregivers in New Zealand including family, friends and significant others involved in supporting a person with a disability in the community. There are four guiding principles: 1) recognise diversity, 2) be proactive, 3) enable caregivers, and 4) be inclusive. These principles will be used by government to evaluate any activity that affects caregivers. Non-government organisations, businesses and community groups can use these principles to guide their work with caregivers and their families. There are five main objectives in the strategy and these are: 1) provide information, 2) protect the health and wellbeing of caregivers, 3) enable caregivers to take a break, 4) provide financial support for caregivers, and 5) provide training and pathways to employment for caregivers.

As part of the five year action plan the Ministry of Social Development has developed "*A Guide for Caregivers*" (MSD, 2009) that provides information caregivers have stated is important. This includes information on financial assistance, having a break, health and disability rights and help with managing incontinence, along with information on housing and vehicle modification. As part of protecting the health and wellbeing of caregivers the Accident Compensation Corporation (ACC) is developing wellbeing and learning programs for informal caregivers. There are also action plans for reviewing and improving respite services for caregivers to enable them to take a break from the caring role. How widely the Caregivers Strategy is known among health professionals is debatable. I have only seen copies of "*A Guide for Caregivers*" in the offices of social workers within the acute care environment. Placing the document in readily accessible areas within

the hospital, including ED waiting areas, along with other useful information is one way of distributing information outside of usual working hours. Jorgensen, Parsons, Jacobs, and Arksey (2010) conducted a study to determine the unmet needs of New Zealand caregivers and concluded the Caregivers Strategy does not address all needs within this important group. The study indicated < 4% of caregivers of people >65 years of age were happy with the support they received.

2.10 National Dementia Strategy

Alzheimer's New Zealand launched the National Dementia Strategy (Alzheimer's NZ, 2010) and action plan in response to a worldwide trend indicating dementia rates are doubling every 20 years. There are eight identified strategic goals in the strategy, the first being to recognise dementia as a national health priority. This will ensure Government funding is allocated to the strategy and its goals. Among the other strategic goals are increasing public awareness and providing access to affordable and appropriate medication. Early diagnosis and management involves development of education for GPs so detecting and diagnosing early dementia is improved. Medical training is seen as a priority to ensure adequate future planning for people with dementia and their families. The development of appropriate services is also seen as a strategic goal and this includes a policy document on ethics and treatment of care for use by service providers (Alzheimer's NZ, 2010). Best dementia care practices for use by DHBs and Primary Health Organisations are being developed and are expected to be released by December 2011 (Alzheimer's NZ, 2010).

Of note in the strategy goals is a section for family/whanāu/ caregivers support that includes financial support along with resources. This supports the continued implementation of the NZ Caregivers Strategy mentioned previously.

Workforce development is also included, with a call for minimal standards developed for dementia specific training of all staff caring for people with dementia. Culturally based skills for dementia care are to be ascertained for both Maori and other ethnic groups to ensure the needs of all people are recognised when developing education packages and resources for people in dementia care employment (Alzheimer's NZ, 2010).

It is clear that there is a call for further support and education for health professionals working with PWAD. I now focus on my area of interest the ED environment.

2.11 Triage in ED

Triage is a process used in EDs throughout the world as a tool to evaluate the severity of need in people presenting for treatment (Edwards & Sines, 2007, George et al., 1995., Lähdet et al., 2009). It is a quick assessment designed to evaluate need rather than diagnosis (Lähdet et al.). Triage originated during war time as a means of identifying soldiers who were able to be treated from those who were not. Over time this process developed into an essential process in patient care (Lähdet et al.).

In New Zealand, as in many other countries, ED triage is a nursing responsibility assisted by the use of the Australian Triage Scale (ATS). The ATS was developed by the Australasian College for Emergency Medicine and is the national triage method for Australia and New Zealand (Lähdet et al., 2009). The ATS was introduced in the early 2000s replacing the National Triage Scale (NTS) which had become outdated due to advancement in treatments and technologies, altering practices in ED (Yousif, Bebbington, & Foley, 2005). Table 2 below illustrates the ATS categories and time expectation to assessment and treatment.

Table 2. Australasian Triage Scale categories and associated times to assessment and treatment. Adapted from Yousif, Bebbington & Foley, (2005).

Category	Time to assessment and treatment
1	Immediate and simultaneous
2	Within 10 minutes and simultaneous
3	To start within 30 minutes
4	To start within 60 minutes
5	To start within 120 minutes

The updated ATS included alterations to category two to capture: patients requiring time-critical interventions; those with potential to deteriorate; that is, ectopic pregnancy; those in severe pain or distress; and those presenting with situational emergencies including violence and self-harm (Yousif et al., 2005).

Category three was also altered to include most bone fractures, head injuries and seizures and category five was reduced to include only minor injuries and symptoms associated with existing stable conditions. Many of the minor injuries formerly in category five were reassigned to category four (Yousif, et al.,2005).Triage tools have been utilised to measure the effectiveness of EDs specifically departmental efficiency, resource allocation, and casemix measure. The ATS provides a performance indicator via the ability to audit and measure the percentage of patients seen within the desired time frame (Yousif et al., 2005). Despite this somewhat prescriptive tool there has been criticism of the variation seen between nurses' application and interpretation of the tool (Considine, Thomas & Potter, 2008; Edwards & Sines, 2007; George et al, 1995; Gertz, et al., 2008; Göransson et al., 2005; Göransson et al., 2008). The level of training nurses get prior to assuming the Triage role is varied resulting in a call to develop National training in New Zealand. In 1997 the Emergency Nurses section of the NZ Nurses Organisation developed the NZ Triage course. Its aim was to meet the educational needs of both rural and urban

nurses in the ED setting. The course is not compulsory and uptake would be dependent on each nurse's perceived need for training outside of the workplace. (New Zealand Nurses Organisation, 1997).

Triage was originally developed to assess physical illness but since 1993 there has been a Mental Health Triage Scale (MHTS) in use in Australia (Broadbent, Moxham, & Dwyer, 2007). The use of the MHTS is however *ad hoc* at best and there is a call for consideration of a national approach to the use of a MHTS. This would ensure equity of service provision to people presenting with a mental health condition. It is of interest therefore that the use of an MHTS is limited especially given the potential increase in presentation of older people with multiple co-morbidities including dementia to EDs.

It is known that hospital nurses are challenged by patients with dementia in the hospital setting (Fessey, 2007). Dealing with challenging behaviours such as aggression, resisting help and hallucinations can cause stress to nursing staff who are ill equipped to manage this in a hospital setting designed to treat physical illness (Fessey). The *NZ Dementia Strategy* (Alzheimer's NZ, 2010) plans to address a lack of knowledge in acute care settings with the introduction of best dementia care practices for use by DHBs and Primary Health Organisations by December 2011 (Alzheimer's Society NZ, 2010).

2.12 Communication in the Emergency Department

Studies that have been conducted relating to communication in ED have focused on measuring differences in patient satisfaction with communication from health professionals pre and post communication training (Edwards, et al., 2006; Taylor, Kennedy, Virtue & McDonald, 2006). Complaints received from patients in the ED have been studied and communication features significantly (Taylor, Wolfe & Cameron, 2002). Often these studies have been initiated by medical staff working within the ED and there are few nursing studies performed by nurses working in ED.

EDs are often described as chaotic, and driven by acuity of patients in a triage environment (Redley, 1996; Pytel, Fielden, Meyer, & Albert, 2009). In this environment it is easy for nurses to focus on clinical rather than psychosocial needs of patients and families, and this has been cited as a reason for deficits in communication (Redley, 1996). EDs have concentrated

on patient satisfaction with their ED experience of late. Satisfaction is a quality outcome measure and as such has been receiving increased attention, especially in the United States of America (USA) where a lot of the literature originates (Watt, Wertzler, & Brannan, 2005). Satisfaction is identified as the ability to meet patients' expectations and patient satisfaction and patient expectation are different: *Expectations are formed prior to the ED visit, whereas satisfaction is determined by perceptions formed during and after the ED encounter.* (Watt et al., 2005, p 13).

Watt, et al. (2005) conducted a study to explore public expectations of ED care and compare these with ED staff perceptions of patient expectations. They used focus groups to collect data from both residents and staff. Results of public expectations were categorised into six themes: staff communication with patients; appropriate waiting times; the triage process; information management; quality of care; and improvements to existing services. In the area of staff communication patients expected staff to "*treat them as individuals, listen to their concerns and provide reassurance*" (Watt et al., 2005, p14). They also expected to be updated regularly at all stages of their ED visit. Some felt staff communication was inappropriate and perceived staff to be unoccupied and conducting personal conversation in earshot of patients (Watt et al.). Staff, on the other hand, felt they understood patients' expectations and communicated well with patients and families (Watt et al.).

Communication expectations of patients/visitors and nurses in the ED was the focus of a research study by Pytel, et al. (2009). Sixty-four nurses and 123 patients/visitors completed a communication needs survey. The goal of the study was to identify any discrepancies occurring between nurses and patient/visitor ranking of importance. Results indicated there were two major differences in ranking between nurses and patient/visitors. Nurses ranked calm voice (nurses speak in a calm voice), and social status (nurses do not make assumptions about your social status), higher than did patient/visitor(s). The top ranking need for both nurses and patient/visitors was that: *nurses keep you informed about what tests and treatments are done* (Pytel et al., 2009). Nurses met patient/visitor needs 62% of the time indicating areas to improve communication.

The top 10 ranking communication needs in the study were:

1. Nurses keep you informed about what tests and treatments are done
2. Nurses answer your questions
3. Nurses listen to your concerns
4. Nurses show you respect
5. Nurses show compassion and genuine concern
6. Nurses speak in a way that meets your language needs
7. Nurses use terms you can understand
8. Nurse give you frequent updates on what is happening
9. Nurses appear to have time to listen to what you have to say
10. Nurses provide comfort.

These 10 responses scored $\geq 80\%$ frequency of very good or excellent responses from patient/visitors. The authors indicate the findings were limited by grouping patients and visitors together and note future research is needed to explore if differences exist between patient and family/visitor responses (Pytel et al., 2009).

To conclude this section Nairn, Whotton, Marshal, Roberts and Swann (2004) reviewed literature on the patient experience in EDs. They identified six areas of concern within this literature: waiting times; communication; cultural aspects of care; pain; the environment; and dilemmas in accessing the patient experience. These occurred despite patient satisfaction levels being high. When looking at the cultural aspects of care Nairn et al. found elderly patients often present with complex problems requiring a holistic approach, compared to the approach of emergency nurses who are more focused on the technical aspects of care. *“Sensory and physical discomfort are often sidelined and the manner in which nurses spoke to the elderly at times showed a patronising and ageist attitude”* (p162)

2.13 Relevance of the study

AD is predominantly a disease of the later years of life. The ageing of our population, along with demographic predictions, indicate the incidence of AD could rise by as much as 2.5 fold by the year 2031 (Tobias, Yeh, & Johnson, 2008). It is therefore likely that EDs will not only see an increase in presentations from older adults but also from those with AD. The ability to readily assess cognitive deficits in these patients and effectively communicate with them and their family will be a vital part of nursing

assessment. This study is relevant to nursing as nurses are the most represented profession in the ED. Nurses spend time with patients and their relatives in this setting and are responsible for monitoring the conditions of patients under their care. Current literature indicates there are problems with health professionals' communication with family caregivers, whose needs are not being met. It is timely for nursing to review its ability in this area to meet the challenges of the next 20 years.

2.14 Contribution to nursing knowledge

Capturing the experience family caregivers have of communication from RNs in the ED, will add to awareness of the needs of caregivers, related to communication, in the hospital setting. This in turn may influence changes in practice as a result of increased awareness, and/or, offer further incentive for research in this area of practice. The study may indicate the need to revise existing guidelines and standards in relation to communication with patients and families, or it may result in the development of guidelines where previously none have existed.

2.15 Summary

This chapter has discussed a model of health communication and how communication methods can enhance or inhibit nursing practice. This model has been linked to research literature on patient/health professional communication where studies have clearly indicated a need to improve the level and skill of communication between patients and nurses. The literature explored to inform my broad interest was in family caregiver satisfaction with nurse communication in the ED. I narrowed my question down to family caregivers of patients with AD to ascertain if knowing your patient has AD makes a difference in the quality of nursing communication with family. Patients with AD have difficulty communicating. Dependent on the degree of severity of disease, patients may appear to be capable of making decisions, passing on accurate history of illness and co-operating with treatment regimes. Further consideration of the literature indicated a gap in research on the actual experiences of caregivers of PWAD when they attended ED, consequently my research question was narrowed down

to: *“What is the experience of family caregivers when accompanying their loved one with Alzheimer’s Disease to the Emergency Department?”*

In the following chapter I outline the study design, including recruitment, methods of data collection and analysis.

Chapter 3. Study Design

3.1 Introduction

This chapter outlines my research design. I first describe the philosophy of the methodology used and why I chose to use phenomenology. Methods of recruitment, data collection and analysis are presented. I conclude this chapter with a detailed discussion of my position as the researcher and my reflections on this.

3.2 Phenomenology

As this research sought to capture family caregiver experience when accompanying a relative with AD to ED a qualitative method was chosen. Qualitative research shows a preference for the analysis of words and images rather than numbers (as seen in quantitative research). There is also preference for unstructured rather than structured interviewing, and for meanings rather than behaviour – where the world through the eyes of the participant is interpreted and documented (Silverman, 2000). When considering the type of methodology to utilise, the question determines the approach taken. I chose phenomenology as a method to gain an understanding of the meaning of the ED experience for caregivers. Phenomenology is described as “*a focus on exploring how human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning*” (Patton, 2002, p.104). Max Van Manen (1990) states: “*Phenomenology aims at gaining deeper understanding of the nature or meaning of our everyday experiences.*” (quoted in Patton 2002, p.104). He also states that experience is made up of reflection on a prior event, one cannot reflect on an experience while it is occurring (or being lived). The act of reflection places the new experience within the context of past experiences, and commits it to our consciousness (Patton, 2002). Therefore, whatever falls outside our consciousness is outside the bounds of our possible lived experience (Patton). In asking participants to describe their experience when accompanying a family member to ED they verbally reflected on that experience, and this reflection brought their experience to life.

Phenomenology has been dominated by the works of the German philosopher Edmund H. Husserl (1859-1938) (Tan, Wilson, & Olver, 2009; Patton, 2002). Husserl introduced the term *lifeworld*, meaning pre-reflective experience. He stated *lifeworld* is not always available to us as it is influenced by that which is taken for granted along with conditioning from past experience (Tan, et al., 2009). In order to understand or take meaning from the *lifeworld* of others Husserl, who was a mathematician before becoming a philosopher, suggested the researcher bracket their own experience (Lindseth & Norberg, 2004). Bracketing is a mathematical term whereby brackets separate one part of an equation from another, allowing focus on one part in isolation of the rest. Bracketing in research therefore enables researchers to set aside their own preconceptions and experiences when reporting the participant experience or view of the phenomena under study (Hamil & Sinclair, 2010). Eliminating all preconception is understandably difficult, as we all view the world through the lens of personal experience. This was noted by a student of Husserl, Martin Heidegger, who embarked on the phenomenology of human *being*, he named this, *Daesin*. *Daesin* denotes the nature and possibilities of being as a person who exists in, and of, the world. In this manner it is impossible to live a life in the world except through acts of interpretation (Tan, et al., 2009). This concept was expanded by Hans-Georg Gadamer (1989). Gadamer argued that when we open ourselves to a question, the understanding we have (resulting from our previous experience), is immediately superseded by exposure to the new experience. Therefore interpretation is a collaborative process between researcher and participant (Tan, et al., 2009). The link between researcher and participant alters the researchers' life view of the world, as a result of exposure to, and interpretation of, the lifeworld of others. The term for this is hermeneutics. Patton (2002) states "*one must know about the researcher as well as the researched to place any qualitative study in a proper, hermeneutic context*" (p. 115).

3.2.1 Hermeneutic phenomenology

Hermeneutic phenomenology is described by Tan, et al., (2009) as "*the process of interpreting and describing human experience, to understand the central nature of that experience.*" (p.2) This methodology has become

popular with nursing researchers wanting to investigate issues of concern and interest in a more holistic manner.

As a nurse researcher employed as a Clinical Nurse Specialist and working with older clients and their families, both within the hospital setting and in the community, I have my own worldview and experience of the ED. I am also a mother and have accompanied my child to ED (as an adult), so have personally experienced ED as family member. This influenced my decision to use hermeneutic phenomenology as the methodology for this study, as it does not distance my experiences from those of others, but rather allows me to incorporate their experience to grow my understanding. I have used the interpretation theory of Paul Ricoeur to analyse the data in this study. The work of Ricoeur built on that of Gadamer by taking into consideration the values, beliefs, and culture, of a specific context of participants (and researcher), as elements to be explored during data collection and interpretation (Charalambous, Papadopolous, & Beardsmore, 2008). Ricoeur rejected the idea of bracketing, allowing the researcher to adopt a more active role when interpreting data by bringing her/his experiences into the study. I will discuss this further in the data analysis section.

3.3 Sampling

I used convenience sampling to obtain volunteers for this study. Convenience sampling is the use of participants who are the most convenient to the researcher and so results of studies using this form of sampling cannot be generalised (Gillis & Jackson, 2002). This form of sampling can also be labelled as volunteer sampling where people are requested to volunteer to take part in a research study. (O'Leary, 2004). Volunteer sampling yields participants with distinct characteristics described by O'Leary as: *those most interested or those most susceptible to any offered inducements* (p110). In my study I therefore hypothesise that participants answering my advertisement had a special interest or desire to report their experiences as no incentives were offered. I advertised for volunteers who were family caregivers of people with AD. Volunteers had to have accompanied their family member to the ED within the past twelve months.

A sample size of 6-10 participants is recommended to obtain sufficient depth to the study (Patton, 2002). The sample size was also determined by

the number of people who volunteered to be part of the study and the timeline available to me. A large sample size is not required in qualitative research which seeks to capture richness and breadth of data to establish understanding (Patton).

Inclusion criteria

To be eligible to participate in the study the person had to have a family member with AD and to have accompanied this person to ED within the last 12 months. The time limit was applied to enhance the recall of participants. I felt that if the experience was over 12 months ago then accuracy of recall may be compromised.

Exclusion criteria

Participants could not be included in this study if their ED visit was over 12 months ago. Exclusion was also applied for non-family caregivers such as friends, neighbours, and formal caregivers that accompany people to the ED (such as nurse assistants from residential care facilities).

3.3.1 Recruitment

An advertisement (Figure 2) for the study was placed in several local community newspapers to encourage volunteers from the wider regional community

Figure 2. Advertisement for study

<p>Public Notice</p> <p>Do you care for a family member with Alzheimer's Disease? Have you taken your relative to the Emergency Department at a hospital in the past 12 months? Are you interested in discussing your experience?</p> <p>I am a nurse researching communication between Registered Nurses and family caregivers in the Emergency Department. I would love to hear from you. This research is being supervised by Victoria University and has ethics committee approval. Please contact me for more information and/or to register interest : Sandy Ridley Ph:</p>
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I also gave a copy of the advertisement for display at caregiver support groups run by the local Alzheimer's Society, and at a caregiver support group run by an employee of the local District Health Board. Information and consent forms were left with leaders of these support groups to hand out to interested parties. I was very aware of the need to protect volunteers from coercion and so left written material with group co-ordinators to hand out. Volunteers were not offered any reward for their participation.

Advertising to attract participants may result in responses from people with a message to relay or a preconceived, definitive stance on the topic. (O'Leary,2004). I found this in two instances during data collection. Two of the participants indicated they had been dissatisfied with their ED experience and were thinking of making a complaint. Rather than do this, they indicated that my advertisement was an opportunity to tell their story. They felt this was a better way of making a statement than writing an official complaint.

3.4 Ethics

This research was approved by the Central Regional Ethics Committee in the North Island of New Zealand (Appendix 2, p 81). As this research targeted caregivers of people with AD, rather than people who have AD, an

expedited ethics application was applied for and granted. Expedited ethics approval is granted for research that is considered to be low risk, or have minimal harmful effect on participants. The reference for this research is: CEN/09/52/EXP. Approval was granted on the 14th April 2010.

Each participant was required to sign an informed consent form that included information about the study (Appendix 3). Information supplied consisted of the purpose of the study, who the information will be available too, confidentiality of the participants, and the ability to withdraw from the study at any time.

When undertaking a study involving human subjects it is important that taking part in the study does not cause harm to any of the participants, studies therefore require a degree of beneficence. Beneficence is the duty to promote or do good (Gillis & Jackson, 2002). Recalling a stressful situation (such as the illness or injury of a loved one) had the potential to cause emotional upset to participants. I ensured this was discussed prior to interview so the participants were able to request the tape be turned off should they desire. One participant became tearful when recounting her experience and the tape was paused to allow her to compose herself. She was given the opportunity to withdraw from the interview but declined and was able to carry on.

This same participant felt it was a therapeutic experience to be able to discuss her experience. She had considered writing a formal letter to have her concerns heard but felt taking part in this study was of more benefit to her. The concept of beneficence or benefit to participants is readily seen in this example.

3.4.1 Confidentiality

I considered it important to reinforce that both the location of the ED, and the participant identity, was confidential and as such they should expect no effect should they need to take their loved one to ED in the future. To protect participant confidentiality I requested they create a pseudonym for both themselves and their relative when referring to them during interview. Interview tapes were kept in a locked container, and transcripts stored on a password protected computer. Consent to participate was written and the consent forms stored with tapes in a locked container.

3.5 Data Collection

Data collection consisted of taped interviews which were later transcribed for analysis. The person who transcribed the tapes was required to sign a confidentiality agreement.(Appendix 1) I personally transcribed two of the interviews. I took scant notes of each interview outlining my observations. I found the process of taking field notes immediately after interview distracting and so committed my thoughts to paper later, allowing reflection. Each participant was interviewed at a place of their choice and each interview lasted no more than 60 minutes. The interviews were held at the homes of all participants at a mutually agreed time.

3.6 Interview

A semi-structured interview technique using an interview guide was used to capture data for the study. The interview guide consisted of five broad questions with further material designed to expand and explore the data as required to maintain depth for analysis (see below).

Caregivers experience of emergency department Interview guide.

The questions and cues in this interview guide are designed to be a prompt only.

Caregiver response will be allowed to flow with minimal interruption from the Researcher in order to maintain authenticity of the experience.

- Tell me about the time you spent in the Emergency Department.....

- How much help did you receive from Registered Nurses?

- Tell me more about this.....
- Can you describe the experience for your loved one.....
- Describe to me how the decision to admit or discharge was presented to you and your relative?
- What advice would you give to others taking their relatives to ED?
- Overall was there anything that could have made your stay in ED easier?

Figure 3 Interview Guide.

Interview guides list the questions and issues to be explored during the interview. They ensure that the researcher (interviewer) follows the same basic line of enquiry with all participants. The use of a guide, rather than set questions, allows the interviewer freedom to probe and explore areas to shed light on the subject under study and is in keeping with phenomenology. The interviewer is free to build a conversation within the subject area (Patton, 2002).

Each interview commenced with the participant being asked to describe the circumstances that led to them presenting to ED. This allowed free flow of information and served to relax and focus each participant on the interview process. In telling their story they appeared to not find the tape recorder an intrusion. I used a combination approach of semi-structured interview and conversation. A combination approach allowed use of a standardised interview format in the early part of the interview, leaving me free to pursue subjects of interest in the latter part of the interview (Patton). Following the first interview I added a final question to the interview guide that asked

what advice participants would give to other caregivers accompanying their loved ones with AD into ED. This served to enhance their reflection of the event and describe things that may have improved the experience. One participant indicated she would have discussed resuscitation with healthcare staff had she realised her husband was “for resuscitation”. Another participant mentioned her brother had rung the ED after her father was discharged to enquire about why he was sent home, as he was still very ill. I asked her to describe this incident to me at the end of the interview as it provided pertinent information that was not included in the interview guide.

Trustworthiness in qualitative studies is an indication of the reliability of the study (Mateo & Kirchhoff, 2009). In order to achieve reliability Lincoln and Guba (1985) present a framework that has been widely accepted as ensuring a quality investigation. This framework consists of *truth value* or credibility, *applicability* or transferability, *consistency* or dependability, and *neutrality*. Truth, value/ credibility translate to whether the results of the study are an accurate reflection of the participants and experiences that were studied. Member checking or returning to participants with a transcript of their interview and the interpretation is the gold standard indicator of credibility in qualitative research. *Assessment to see if the data make sense through member checking decreases the chances of misrepresentation.* (Krefting, 1990, p.219) McConnell-Henry, Chapman, & Francis (2011) argue that this contradicts many of the underpinning philosophies in phenomenology, rather they suggest strategies for successful phenomenological interviewing and listening with interpretive intent as a more useful way of checking understanding during the interview process. This is the method used for my study (McConnell-Henry et al.). An audit trail is a method of ensuring transparency of interpretation by clear process documentation so the reader is able to readily see how interpretations have been made from the data provided (Mateo & Kirchhoff).

Evidential examples of the analysis method are provided as proof of interpretive process. Transferability is not the goal of a qualitative researcher and so it is left to the reader to ascertain if the results of this study can be applied to their area of practice (in the case of a RN).

Information required to accurately assess this is gleaned from sufficiently detailed description of the research design and analysis (Mateo & Kirchhoff). I have provided this detailed description in Chapter Three by describing the research design and analysis methods. The design and analysis methods can be applied to other studies. Neutrality or confirmability is the ability of a study to report the results devoid of researcher bias (Mateo & Kirchhoff). The analysis method used in this study requires the use of reflexive practice by the researcher. I acknowledge my growth and the assumptions I brought to this research as part of the reflexive process.

3.7 Te Tiriti o Waitangi (The Treaty of Waitangi)

The Treaty of Waitangi is the founding document of New Zealand and was signed in 1840 between Maori Chiefs, and representatives of the British Crown. The Treaty recognises New Zealand's bicultural nature giving Maori the same rights as British subjects. The Treaty has three guiding principles: protection, partnership, and participation, this is discussed in chapter three. I consulted with the Maori Health department at the regional hospital where this study took place to seek advice about working with any Maori participants. There were no participants who identified as Maori in this study.

3.8 Data Analysis

As mentioned earlier I have used the interpretive method of Paul Ricoeur (1981). This method acknowledges researcher growth and change during the process of data interpretation. As a novice researcher the principles of Ricoeur's theory seemed to resonate with the data I collected. In transcribing interview tapes I was able to listen again to the participants' voices, and transcribe verbatim what was said. The subtle nuance of non-verbal cues had disappeared as I was no longer in front of the participant so was relying only on the spoken word and text (Tan, et al., 2009). Thus it is not possible to recreate an interview in its entirety. In transferring spoken word into text what is left is only an impression of that interview. This was especially true when reading transcripts sent from my transcriber (Tan, et al.).

I have utilised Tan, Wilson and Olvers (2009) interpretation of Ricoeur's theory of interpretation to frame my data analysis (Figure 3). The analysis is

broken down into three main fields of understanding: text and distanciation; interpretation and understanding; and appropriation and explanation. I will provide a brief explanation of each of these fields and then a more in depth analysis of how this was applied to my research data.

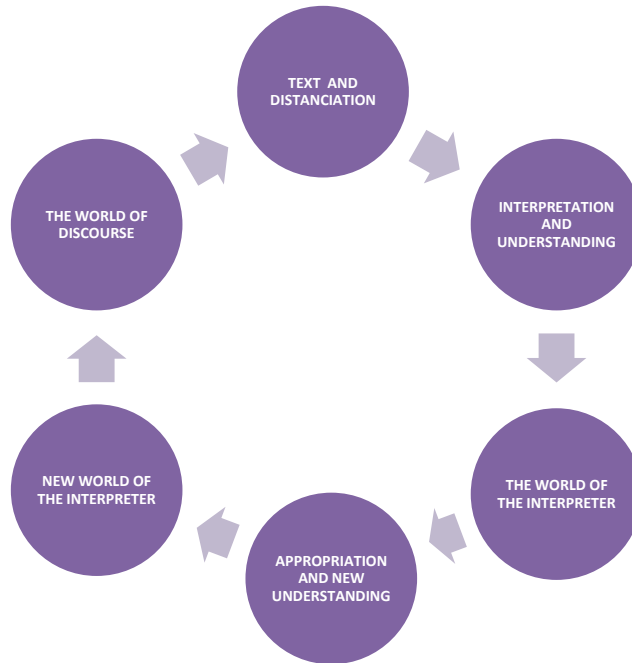


Figure 4. Ricouer's Theory of Interpretation adapted from Tan,H., Wilson, A., Olver, I. (2009). Ricouer's Theory of Interpretation: An instrument for data interpretation in hermeneutic phenomenology. *International Journal of Qualitative Methods*, 8(4), 1-15.

3.8.1 The world of discourse

The first stage of data analysis was collecting data. As mentioned previously, (Section 3.4. Data Collection) I conducted taped semi-structured interviews with each participant. Demographic questions were asked at the beginning of each interview, age, sex, relationship to family member, length of time they had been caring for the family member. This allowed me to gain a background about each participant. I asked each participant to describe their visit to ED and how this affected both them and their family member, the benefit of this approach is mentioned also in Section 3.4 Data Collection.

3.8.2 Text and distancing

Understanding text is fundamental to Ricoeur's theory and the nature of the relationship between speech and writing, and role of the writer and the reader, in comparison to that of the spoken word. Ricoeur (1981) believes that once discourse is converted to text it changes and the meanings can be altered. Non-verbal, speech nuances, and posture, that give meaning to the spoken word during conversation are not seen in text. Many readers can read text, altering the original meaning and intent subject to reader interpretation. This distancing of text from the oral situation *causes a change in the relationship between language and the subjective concerns of both the author and the reader* (Tan, et al., 2009, p7). Ricoeur (1981) mentions four principles of *distanciation or distancing*:

“(i) the transcription itself and the meaning of the written word: (ii) the relationship between what has been written and the intent of the person who wrote the text: (iii) the meaning of the text beyond its original intent and (iv) the new interpreted meaning of the written word and the audience” (Charalambous, et al., 2008, pg.639).

My initial assessment formed what is called a *naive reading* that is a simple interpretation of what is said (Lindseth & Norberg, 2004).

There was a sense of being part of the experience of each participant and as I had interviewed each one I felt I knew them, by being a listener, and also engaging in conversation during the interview. As a visual person (learning by seeing and recall of what is seen) reading the transcripts and listening again to the taped interviews brought a picture of the participant

and the interview environment back to me. However, like Ricoeur (1981) stated there was a distancing I noticed when working with each text, I could not recapture the full interview experience, but rather was reliant only on my recall and interpretation.

3.8.3 Interpretation and Understanding

My initial interpretation involved simply reading and re-reading the transcripts, and concurrently playing the tapes, to ensure written material matched recorded data. This allowed me to connect with the data in a more in-depth manner. With naive reading the text is read several times in order to grasp meaning as a whole. The reader must be open enough to allow the text to speak to them, becoming touched or moved by what is revealed. During this time it is necessary to move from a natural attitude to a phenomenological attitude (Lindseth & Norberg, 2004). I found participant accounts of their experiences moving, as they had not always been optimal. In some ways I felt they were being too easy on health professionals, seeming to be resigned to what occurred, even if it was extremely frustrating. I was unable at this stage to move beyond what was said into any deeper meaning. Initial themes are presented in Table 3.

Table 3. Naive interpretation

Example	Theme Colour coded
“I have found the nursing staff don't seem to understand dementia at the hospital at all as well as you think they would. I suppose they don't come across it a great deal.”	Nursing staff lack of knowledge
“They did explain a wee bit but they kept going away.”	Left alone Lack of information
“.....they seemed to expect us to keep him quiet and keep him settled....”	Perception of responsibility for management in ED
“At one stage they said to go and wait out in the family room but the caregiver from the rest home stayed with him.”	Removal of spouse to the family room.
“He really needed to be in a room with a door instead of a curtained area, I suppose – I don't know if they have a room like that?”	Inappropriate environment
“It was vague. It was just that he was – everything was clear, you know, and that was sort of it, and I thought well, you know, what do we do with him?”	No in-depth information given or suggestions for further monitoring or management (post seizure).
“ The experiences we have had, the environment, the illness....seems to throw Dad into quite a lot of confusion and distress...”	Environment, illness, confusion, distress (delirium?)

I used different colours to highlight the emergent themes during this process. I applied these colours to all interview transcripts to establish commonality. The four initial emergent themes were communication, environment, loss of control and staff lack of dementia knowledge. This is illustrated in Table 4, p39.

Table 4. Initial themes

Communication	Not listening	One way communication Not being listened too
	Lack of information	Lack of information Spouse told to give information to rest home/ageism Minimal information given to spouse No in depth information given or suggestions for further monitoring or management (<i>Post seizure</i>) Information not given unless asked for Poor general information
Environment		<ul style="list-style-type: none"> Inappropriate environment Lack of privacy It was easier to get him back to the home... where he knew where he was and reasonably familiar.
Loss of control		Sense of loss of control (said more than once) Decisions made to carry out diabetes test rather than ask for clarification from the family caregiver Loss of power
Staff lack of dementia knowledge		Expectation that staff would recognise non-verbal signs of pain Nursing staff failure to recognise cognitive problem Need to be proactive with staff regarding the cognitive ability of their relative

The next stage of the analysis moved from the naive interpretation to a more phenomenological interpretation that represented the feelings that emerged from what was said. At this point I had sent material to my supervisor and she agreed with my initial interpretation. With her assistance I was able to delve further into the text and reveal an overarching theme of *being sidelined*. Within the overarching theme were three interrelated subthemes: invisibility, abandonment, and resignation (see Figure 4). These themes were then linked back and checked against the naive interpretation themes to validate results. Tan, et al., (2009)

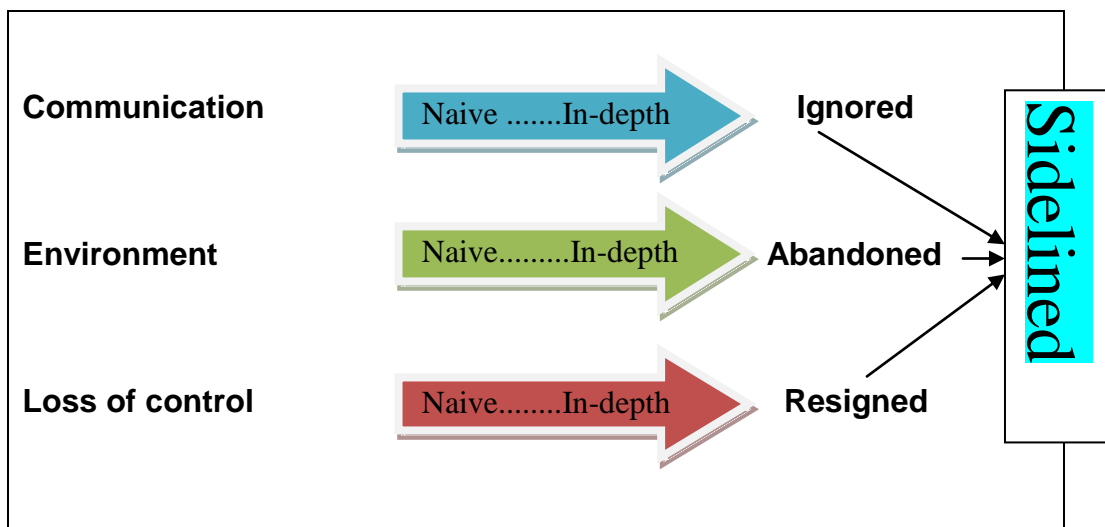


Figure 5. Naive Interpretation link with In-depth Interpretation

I incorporated the fourth naive interpretation of *staff lack of dementia knowledge* into *environment* as this formed a key part in the experience of each participant. Not all participants discussed a staff lack of dementia knowledge, but all commented on process and environment. Staff form part of the environment and the skill of staff impacts on both the receivers of care, and their family.

3.8.4 Appropriation and Explanation

The third and final part of Ricoeur’s interpretive analysis process is that of appropriation where the researcher can identify personal growth and learning from their experience as a participant in the research. I used a process of reflexivity to explore my personal views prior to undertaking this research. I work alongside the environment under study (Clinical Nurse

Specialist in the Older Peoples Service) as part of a rapid response interdisciplinary team. I have observed the practice of health professionals on a superficial basis when I have been consulted to assist with care planning or discharge of complex elderly people, from either ED or the Acute Assessment Unit. Process and procedure influence decision making depending on the confidence and skill level of the health professional. Prior to my current role I was employed as a Discharge Co-ordinator in the medical wards at a tertiary level hospital in a larger city in New Zealand. I worked with family members to plan discharge of complex patients and attended many family meetings and multi-disciplinary team meetings centred on treatment, and discharge planning. This past experience was brought to my research.

3.9 Reflexivity

Reflexivity is described as the identification and acknowledgement of one's place and presence as a researcher within the research. One can then use this insight to critically examine the research process (Underwood, Satterthwait, & Bartlett, 2010). I have reflected on my place as a nurse researcher and the effect this had both on the quality of the data I collected, and my interpretation of that data. I advertised myself as a nurse conducting research so all participants were made aware of this prior to volunteering. I found myself stating that I did not work in ED during the initial telephone discussion I had with each volunteer prior to interview as this was important to further encourage participation. I felt if the participants thought I worked in ED they may not wish to disclose their experiences should they have been less than satisfactory. None of the participants who took part in the research were known to me prior to this research.

I have also reflected on being female in relation to the participants (five females and one male). The only male participant was the spouse of a person with AD. His experience of ED was different to the others insofar as he was entirely satisfied with all interactions. His interview indicated that he deflected most information seeking by health professionals from himself to his daughter (who was also present), or the residential facility manager (his wife lived in residential care). He became an observer in the process rather than a participant. He seemed to leave most decisions around the care of his wife to the health care professionals and his daughter and this was

usual for him. Once this was established I found it hard to probe for more information about his feelings. While reading and re-reading his transcript later he revealed a sense of unquestioning acceptance of the health professional opinion. I did not find the same degree of difficulty interviewing the female participants who more readily engaged in conversation. Underwood et al. (2010) mention that it is suggested that researchers and participants share the same attributes in terms of gender and ethnicity for example, to enhance the quality and meaningfulness of results. Almack (2008) conversely argues that the researcher does not have to share commonalities with research participants to positively influence data, rather the interaction between researcher and research participant is what shapes the depth of data. I found myself identifying with participants who were daughters of people with AD as I had more in common with these participants in general and this appeared to influence the richness of data obtained by these participants in relation to that obtained from the others. Daughters were both younger (closer to my age), and more articulate than the older participants. The sense of frustration with ED process and experience seemed greater in these participants. Older participants seemed to have a more resigned attitude. I discuss this further with transcript examples in Chapter Four – Research Findings.

Each participant was interviewed only once so opportunity to explore any relationship formed with the participant was fleeting. As a novice researcher I felt my experience both in achieving volunteers for my study and gaining richness and depth of data for interpretation was influenced by the participants having much in common with myself. All were of the same ethnicity as myself and we shared a common understanding of both language and culture. This allowed me to feel at ease throughout the process of interview.

The personal learning I achieved as a result of reflection on the process allowed me to see how I responded as a researcher and some of the assumptions I brought to this research. During the process of interpretation it became clear that some of the experiences shared by participants mirrored my own feelings as a family member in ED. What challenged my thinking was the ability of participants to justify the actions of health professionals even though it was having an adverse effect on both them and their loved ones.

3.10 Summary

This chapter has outlined hermeneutic phenomenology and how this was used to collect data on the experience of a family caregiver in the ED. The analysis method has been presented in detail with examples of each stage of Paul Ricoeurs interpretive analysis method described and illustrated. This provides a detailed audit trail to enable the process to be replicated in other studies.

I have also provided a record of my growth and development as a researcher and how this influenced my interpretation of findings using reflexivity.

Chapter 4 Findings

4.1 Introduction

This chapter presents the findings of participants' experience of ED. Most caregivers found their ED experience frustrating and frightening with little communication from health professionals and long periods waiting with their relative for attention and information. Not being included in conversations between healthcare professionals and the PWAD caused concern. Staff lack of knowledge of dementia meant even though caregivers expressed a need to speak on behalf of the PWAD this was often ignored. An overarching theme of *being sidelined*, integrated and interlinked with subthemes of *being ignored*, *being abandoned*, and *being processed* resulting in *being passive observers* of care for the PWAD in the ED. Figure 4 (p.45) demonstrates the connectedness between key themes and subthemes.

4.1.1 Participant Profiles

Six people responded to my advertisement in local papers and all met inclusion criteria. Table Five below provides a profile of each participant. None of the participants had their relative with AD living with them at the time of interview. Of the six people interviewed only one had her relative still living independently in the community the remainder supported their relative in residential care facilities and one participants husband had died. All participants had cared for their relative in the community prior to them entering residential care for periods ranging from two years to eight + years.

All participants with the exception of one were female. The one male was the husband of a person with dementia who had been in residential care for three years. This gentleman lived alone and his daughter and son-in-law seemed to be the primary contact used by the residential care facility to alert the family to any problems his wife had. He had accompanied his daughter to ED to meet his wife after the family called him to say there had been an event at the care facility. He therefore was slightly removed from the main communication as his daughter took more of a lead role in ED. This only became apparent during the interview so the data collected from this participant was not able to be utilised as well as that of the remainder

of the participants. Participant selection for this research was by voluntary selection and so can be described as 'secondary selection' over which I as a researcher had little control. It has been suggested that researchers who conduct interviews of little use to the research do not have these transcribed but retain them in case the information contained becomes useful at a later time. (Denzin and Lincoln, 1994). I chose to transcribe this interview however as there were some informative sections within the data that supported the research however there was significantly less useable data obtained when compared to all other participants.

Table 5. Participant Profiles

ID/ Gender	Age	Relationship to person with AD	Years spent caring for relative	PWAD residential status	Reason for ED presentation
B1/F Bonny	70+	Wife	8+ yrs	Residential care	Seizure
B2/F Bridget	40-49	Daughter	0-2 yrs	Independent living	Diarrhoea/GI Bleed (multiple presentations)
J1/F Jocelyn	50-59 yrs	Daughter	2-4 yrs	Residential care	Fall -fracture
C2/F Catherine	70+	Wife	6-8 yrs	Residential care/now deceased	Fall -fracture
B3/F Barbara	60-69 yrs	Daughter	4-6 yrs	Residential care	Hand injury
P1/M Peter	70+	Husband	Years not specified	Residential care	Vomiting/fall

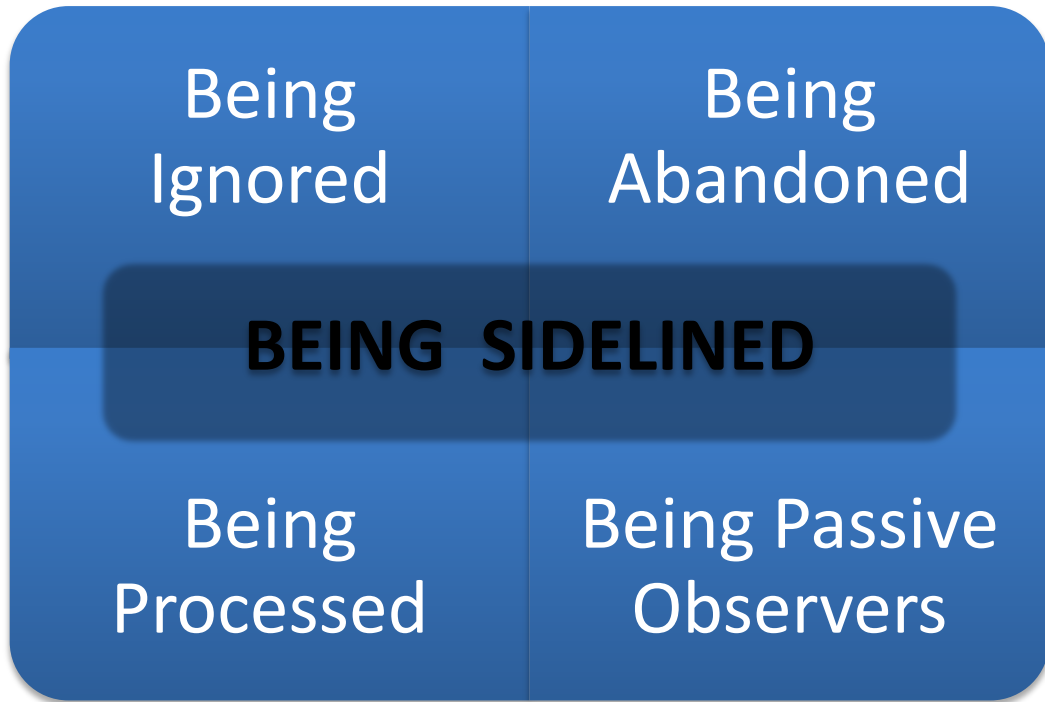


Figure 6. Findings Representation

4.2 Being Sidelined

I felt we were a bit sidelined.

The overarching theme was a feeling of being *sidelined* in the acute ED setting. Being sidelined was expressed in a number of ways, and this was brought about by the actions of the ED team. In reference to the individual experience of each participant health professionals were grouped together and referred to as *they*. Depending on the reason for presentation participants were sidelined by being taken away from their relative. This particularly occurred when the relative required more instant action from the healthcare team.

They took him straight into a room. Catherine, 25.

They removed me from the Emergency Department. Catherine 43-44

Removing participants from the person being treated was expected and accepted by those affected, even when they were not informed of process. When the PWAD was accompanied by a formal caregiver (e.g., a caregiver

from the residential care facility) it was this person ED staff deferred to for information and communication rather than the family member present.

They said to go and wait out in the family room, but the caregiver (from the residential care facility) stayed with him. Bonny 123-124

Participants shared there was little acknowledgement by ED staff of them throughout their ED experience. This was further evidenced on discharge where paperwork was passed on to them to deliver to staff at the residential care facility.

They did give me a note to take back to the home, which I still haven't read because it was sort of whisked away – they sort of gave it to me and said, 'give this to the home' and I intended to read it but by the time we got him into the car... Bonny 123-128

Further to this there appeared to be scant information given to participants for ongoing care. This led to feelings of desperation. The ongoing nature of one participants experience was not taken into account at all even though she had presented with her PWAD on several occasions with the same complaint.

I went and took him back in absolute desperation, it's the worst I have ever been in with this kind of experience with Dad. I just felt so distressed and frustrated because he had undiagnosed diarrhoea, I couldn't manage it – I wasn't a nurse, I didn't know what to do... Bridget 70-74

4.3 Being Ignored

Ignoring the family member when interacting with the PWAD was a strong theme all participants connected with their experience of ED. This also strongly links with being sidelined.

And I'm not questioning their work ethic or...I am not saying they shouldn't be having a chat but I'm saying don't forget about us

people sitting in the cubicles and not knowing what the hell is going on. Bridget, 443-446.

Participants referred to staff continually communicating with the PWAD rather than the caregiver. This led to concern about misinformation and potential inappropriate treatment. Participants were concerned about the risk of inaccurate medical diagnosis and treatment due to staff reliance on inconsistent information from the PWAD.

Whereas I know that what Dad is telling them is not correct so, you know, if they're basing what they are going to do, their next step on that, you know, that's my concern, is that because I know a different reality, they're kind of interrupting and telling me I am a difficult family member. Bridget, 127-131.

I kept saying to them that she actually didn't know anything about what was going on. So I suppose, you know, at that point perhaps they could have spoken more to me than to her – I sort of felt a little bit strange that they were talking to her. Jocelyn, 38-41

Participants attempted to interact with ED staff on occasion to provide more accurate information, but even when the PWAD deferred questions directly to the family caregiver they were still ignored by healthcare professionals.

Well they still sort of looked at me as though 'well, why are you speaking for her?' and they kept talking to Mother; and Mother was sort of saying, 'you tell them because I can't tell them. You tell them. Barbara, 155-157.

You have to try and get through to the reception and to the staff that they are dealing with a person who does not understand why they are there or anything that is said to them; and that you have to be able to speak on their behalf and, you know, the quicker we can get

through this and away from here, the better for everybody. Barbara, 271-275.

Staff knowledge of dementia appeared limited. The expectation that everyone will follow a pre-defined set of rules such as dressing in a hospital gown and waiting on a trolley to be seen was clearly in conflict with reality especially when the PWAD was in the advanced stages.

We wrapped him in a rug because all he had on was his incontinence knickers and popped him in the car and drove him back to the home because he just wouldn't stay still and nobody seemed to know what to do with him. Bonny, 74-78

Staff in ED seemed unable to manage moderately impaired dementia patients with behaviours outside what is considered normal.

And the hospital were very ... in A&E they were very good but they don't ... they're not set up to look after a man that wants to walk all the time and has no idea where he is and what's happening and didn't want to put a gown on and they sort of couldn't quite deal with that; he didn't want clothes on and he didn't want things. Bonny, 51-55

Concern was expressed when speaking *on behalf* of the PWAD and risking being thought of as interfering by health professionals. There was the perception of a line between participants and the ED staff.

It is that line between being a family member there and not wanting to interfere with what they are doing and recognising they're professionals, they're dealing with Dad, they know what they are doing, I don't know what they are doing. Bridget, 205-208.

Lack of information or inclusion in the process of assessment and treatment led to a sense of needing to proactively seek information and clarification. Being ignored meant information was not given unless requested.

You need to be questioning and you need to be asking all of the time through the whole process, so don't just sit there and wait for them to tell you what is going on and what you are going to do – just constantly ask them, because otherwise it feels like you do get lost. Bridget, 349-352.

Being ignored made participants feel not part of the process and they had no purpose in being there. It was upsetting not knowing what to do.

In the early days I kind of used to feel really awkward, you know – everyone's busy with Dad, I don't know what to do, I don't know where I should be, you know, you kind of...and so in those early days of not knowing how the system worked it's quite scary and quite ... you know, you just don't know what to do, you just don't know, it's all really upsetting and really very difficult. Bridget, 454-459

There were feelings of being ignored by health professionals who were following protocols. The statement below was in relation to a participant asking if her mother could have something to eat as she had waited a long time. The response from the nurse indicated that she couldn't eat as she may need to have surgery.

I knew that surgery wasn't going to be on the agenda, I knew that because I had already been talking to the doctor in [town] and I knew what we were there for and I knew we'd faxed everything through so I didn't argue with her, I just sort of said, 'well, I don't think that will be the case' and thought, well, no point in making an issue, they're obviously not going to ... they have a standard procedure and they're not going to change that for one person; so we'll just go and sit down. Barbara, 17-18

Incorrect assumptions were made by Triage staff in response to participants trying to advocate for the PWAD. Participants felt unable to correct these at the time, so much so that they allowed unnecessary tests to be carried out on the PWAD.

Mum's not feeling well, she's feeling a bit lightheaded, she needs some food'; 'oh no, she can't have any food'; 'oh, she's diabetic' and they decided that she had to have a diabetes test right then and there as well. Barbara, 42-45

The participant in this case indicated at no point did staff ask her if her mother was diabetic but went ahead and tested blood sugar levels to see for themselves. This need for staff to *see for themselves* is also illustrated in another participant experience. The perception was that ED staff may feel the participant description of events was not to be trusted.

And I guess, you know, that's what I've learnt: that when Dad's vomiting this stuff I'm taking it with me, I'm taking buckets of it with me so I can say to them, 'look, this is what is happening' because [if] I don't take that in there and say 'this is what's happening' it doesn't seem to, you know, they have to actually see it to have that ... yeah, to see, to believe it almost, is how I feel. Bridget, 220-224

Within ED nurses ignored advice from a participant on the difficulty of inserting an intravenous cannula in her PWAD. Nurses rated their skill higher than the others who had tried and failed before. Subsequently they attempted the cannulation, (despite advice from the participant indicating difficulty with this procedure during previous admissions), and failed in their attempts. This caused distress to the participant who felt the PWAD had been unnecessarily hurt in the encounter and that her advice had been ignored.

But they normally say, 'oh well, we're normally pretty good with this, we're sure we'll be ok' but they're kind of saying ok we're listening to what you're saying but not really, but we're not going to change

what we do and they can't get a line in most of the time so it ends up being two or three different people, one person will try and then they'll get the supervisor Bridget 155-159.

Being ignored was seen also in a lack of staff identification. Participants indicated they had little knowledge of who they were speaking to at times. Staff identification labels were not easily seen and often the staff did not introduce themselves by name.

I don't know who they were, they didn't introduce me very well and they must have told me in a blur and the surprise of all of it I don't really remember, I couldn't see any labels on them so that would have been quite useful to sort of have that a double check to see who they were or their ... yeah, their position within the hospital would have been quite useful because I am a visual person and I quite like the fact that if you see something like that on a person you kind of refer to it if you've forgotten who they are. Jocelyn, 31-36

Not being informed of what was being done to the PWAD was another source of participant concern.

They must have been giving her something through the line that they had put in to help her sleep or just to take away the pain; again, I wasn't aware of what they were giving her. Jocelyn, 231-233

Participants also mentioned being stressed or in shock themselves when accompanying their loved one to the ED. All presentations were due to either an accident resulting in an injury or an acute illness. Stress was verbalised as:

.I've always considered myself to be quite a well prepared person but it did throw me quite a lot. Catherine, 73-75

I suppose, it's just that stress of watching Dad in pain. Bridget, 160

This stress was not acknowledged, at any time, by health professionals in any substantial or supportive way. Being ignored is connected to this lack of acknowledgment of the participant or their stress by any of the health professionals in ED

4.4 Being Abandoned

Coupled with being sidelined and ignored was an added dimension of feeling abandoned. All participants spent long periods of time with no contact from health professionals. During the wait participants remained with their loved one alone without knowing when they would be seen again and by whom. Following each brief contact there was a long period of again being alone waiting.

No, they just went away and we just sat there. Bonny, 241

They sort of did say what they were going to do with him but it was a bit vague and then they all wandered off and we just sat there keeping him down on the bed. Bonny, 325-332

There have been situations where we have been left for hours in the cubicles without seeing anybody. Bridget, 436-437

And we sat there and we watched and we waited. Barbara, 93-94

The others had to leave my mother there and off they went to do their thing and they said to me it would be a while before my mother was attended to. Jocelyn, 47-49

During this time alone there was a feeling of having to fend for themselves both keeping the PWAD comfortable, and attending to their needs. None of the participants spoke of calling for aid but most indicated staff appeared to be busy. Perceiving staff to be busy appeared to be a factor in not wanting to request assistance and/or information.

I feel like they're just so busy, they really can't spend the time with us. And I mean I've been in situations where Dad has started

vomiting this stuff and so I've got the little vomit bucket thing but it's full and I'm sort of looking and trying to find other things and I've gone out. It has been many, many times when I've been there with Dad and he's had the initial assessment and left him. The nurses have done what they needed to do and gone and then just nobody comes back. Bridget, 181-186

Participants had no respite during the waiting period feeling they were unable to leave their relative alone. They were unable to attend to their own needs for fear of harm coming to the PWAD who would be left unattended.

She could have wandered off anywhere. I had to take her through to the toilet when she needed to go to the toilet but I couldn't go off and do anything else, I had to stay with her. Barbara, 136-138

Not knowing procedures and being left alone increased the feelings of stress among participants. Three spoke of gaining support with the help of St Johns' volunteers working in the area. It was these volunteers who provided much needed information and advice in regard to ED procedures. They also provided a *human face* that acknowledged the stress that people are in when they present to the ED with a sick relative. They provided tea, coffee and snacks along with information.

The people that have made the most difference to me in that department have been the St John's people who have been outstanding ... and they will come and give you that little bit of personal, you know, 'can I make you coffee?' 'Can I offer you a chair?' Bridget, 450-454

*Well, I actually asked through the St John's person and she was helpful to give me somebody and I sensed that I was using her more than I was using the staff to find out any information. (297-298) I felt quite safe to know that she was there (St John's volunteer). Had she not been there, it would have been a different scenario altogether.*Jocelyn, 305-306

Umm they took him straight into a room and immediately I was met by St John's, who came and gave me a cup of tea and a big cuddle.
Catherine, 25-29

The psychosocial support that was offered by St John's volunteers seemed to play a vital part in the comfort of caregivers. It was this support that was un-met by any of the ED staff themselves. One participant perceived that the staff did not need to provide psychosocial support as they had the St John volunteers to do that for them.

And I didn't have any tea or anything like that; so this lady kindly said, 'well I don't think I'm supposed to feed you but I will' so she sort of said there's some sandwiches in the fridge so, you know, that side of things again it was very nice that they had prepared- well, she was thinking of my welfare but I sort of wondered if the staff could have- well, I suppose they don't need to because they know that her role is there to do that but again, I don't recall them coming very frequently to check on Mum. Jocelyn, 73-80

4.5 Being Processed

Procedure appeared to dominate interactions with both the caregiver and the person with AD. There was a sense of being a part of the process rather than an individual within the process. Process took precedent over communication.

You kind of feel like you're being moved on like a cattle truck.
Bridget,
So I know that that's the way the hospital system works but I also have options and look, , it would just be great if someone said at the moment we're looking at half an hour or an hour wait. I know we're in that queue with all those people and I'm not expecting them to short-circuit the queue because of Dad but I just, sometimes that process there is, and of course the reality of it is if Dad is sick in

there well then he gets shunted in there really quick. Bridget, 278-283

Repetition within the admission process was also noted. The need to answer the same questions more than once was seen as frustrating. There was also a perception that previous attendances and admissions were not routinely checked by staff when gathering information about the PWAD. Past medical record notes were not consulted prior to seeing the PWAD. This led to differing opinions about each presentation. Each presentation to ED was seen in isolation to other recent presentation/s.

Dad's got quite a history now, going in there – and when I say to them, 'Dad's been in here several times before', I understand the ... because I just assumed they would have a computer system, that they could go to the computer system and bring his notes up and see; I'm not sure whether they don't read all the notes or whether they only read the discharge summary or have access to the discharge summary but they certainly don't seem to open to review the past notes Bridget, 309-321

It was also noted there was repetition in information seeking from ED to the wards with the same information being collected in each setting. This is difficult for a PWAD who may not be capable of giving information.

And then the other thing that I've found is that when I've gone through all the stuff in ED and then been admitted to the ward, and then we have to go through a whole other process. It's like what we have already done has gone now and we have a whole lot of admittance [...] to go through and again, Dad doesn't- he can't answer the questions that they're asking him. Bridget, 391-396

It appeared that even documentation relating directly to an admission was not consulted during the ward admitting procedure requiring further repetition. Participants acknowledged that the PWAD was adversely affected by these processes due to an inability to answer questions.

4.6 Being passive observers

The feelings of being sidelined, ignored and being part of a process rather than an individual within the process led to passive responses and behaviour by participants. Participants felt a sense of disempowerment within the system. It was taken for granted that they would wait and at times not be listened too. There was a tendency with some of the caregivers to justify things they were upset about and discuss *understanding* as part of the process.

I think with most of us like myself when you got to hospital you do what you are told or listen to what you are told. Peter 92-93

I sort of was unhappy in some areas but I just sort of left it and thought oh well but perhaps it's just me being sensitive. Jocelyn 276-278

And I suppose, you know, again I do recognise that from their point of view, they must have a lot of family members who would be anxious and stressed and, you know, not wanting not wanting them to hurt them and they probably deal with a whole range of different issues and I can accept that. Bridget, 151-155

Feeling unable to connect with staff because they were busy was another theme that led to passive behaviours and reluctance to seek out staff for information/ assistance.

Being aware, of course, that everyone else is busy and you don't want to take too much time that people might need the care better, faster or more efficient more urgently. (276-278)I tended not to bother the staff, I guess, because they were busy and they looked busy. Jocelyn, 151-152

I feel like they're just so busy, they really can't spend the time with us. Bridget, 181-182

There was further evidence of passive behaviour having the potential to increase risk to the PWAD through not disclosing information that was leading to concern over treatment methods. In the quote below the participant was concerned that the PWAD was being sedated and knew that this could cause other problems.

They just said they would sedate him to do this. That was ... I just thought, well, I suppose that's what you have to do with him the way he is, it just seemed to be a practical thing to do. But I was a bit bothered about how he'd react to it he does get a bit strange when he's sedated they don't have him on very high in the way of sedation at the home. He's left because it makes him stoop more and the more stooped he is the more he's likely to fall over. I don't know, he's ... it sort of makes him get a bit grumpy. Bonny, 292-298

4.7 Summary

The findings in this chapter reveal stories of distress and experience of being sidelined within the ED. Each subtheme is supported by statements from participant transcripts. In this way I have sought to validate my interpretation of the findings. The overarching theme of being sidelined permeates through the subthemes linking to a sense of being ignored, abandoned, processed and being passive observers within the ED setting. The actions of healthcare professionals are responsible for participants expressing dissatisfaction with their experience.

Chapter 5 Discussion

5.1 Introduction

A further literature review was conducted following analysis of data. This literature as well as literature from the initial search is used here to synthesise and link the findings to existing knowledge on PWAD in acute hospitals. In this chapter methodological issues of validity and reliability are discussed along with implications for professional practice. I also reflect on my personal learning experiences and make recommendations for practice and further research.

5.2 Being Sidelined

This study aimed to interpret the experience of family caregivers of a PWAD in ED. The main finding was that of being sidelined by health professionals in this setting. Sideline is defined by the Oxford dictionary figuratively as:

"...on (or from) the sidelines in (or from) a position removed from the main action." (The New Zealand Oxford Dictionary, 2005).

Participants in this study did not feel they were part of the assessment or treatment of their PWAD. This was reflected in the way they were treated by ED health professionals. They sat and observed their surroundings rather than contributing to the experience. The core theme of being sidelined was inter-related to subthemes of being ignored, being abandoned, being processed "like in a cattle truck" and being a passive recipient of process and procedure.

This resonates with a sense of being unimportant and perhaps an inappropriate presentation to ED. Patients presenting to ED, for what health professionals perceive as inappropriate reasons, are at risk of being judged as time-consuming and unrewarding, and therefore receive less attention than patients perceived as being appropriate (Sanders, 2000). Participants took on the role of the patient as surrogates and felt they were less worthy of attention than other patients, for example those with heart problems. This feeling of being lower down the severity scale may have credence when looking at health professional attitudes toward people presenting who they deem to be inappropriate. The definition of *inappropriate* is subjective and relates to the judgement of each health professional, but in general is

associated with conditions that are not deemed to be of an urgent or life threatening nature (Sanders, 2000). Attitude toward inappropriate patients results in nurses feeling less sympathetic and frustrated, with corresponding loss of motivation to attend to this patient group (Crouch & Dale 1994, cited in Sanders, 2000). Participants in this study reported limited contact from nurses, lack of information and feelings of not being recognised as important by healthcare professionals.

The reason for ED admissions of patients with AD was explored in a study by Nourhashémi, et al., (2001). They concluded the majority of admissions were related to behavioural problems followed by falls and gastrointestinal problems. In my research participant reasons for ED attendance were injuries from falling (three), and gastrointestinal problems (two). The other one presented to ED following a seizure. These problems were not inconsequential so the feeling of being less severe than other patients was challenging for the participants.

5.3 Being Ignored

Being ignored was indicated in several ways one of which was with ED staff's apparent lack of knowledge of dementia. There was a tendency for them to speak directly to the PWAD rather than include the participant in the interaction. This supports the call for workforce education for all staff working with people with dementia as outlined in the *National Dementia Strategy* 2008. Information supplied by a person with dementia may be inaccurate. In a study by Han et al.,(2011) the effect of cognitive impairment on the reported accuracy of the presenting complaint and discharge comprehension in older ED patients was examined. Findings indicated delirium superimposed on dementia is associated with decreased accuracy of presenting illness and decreased comprehension of ED discharge instructions. Delirium is an acute, mostly reversible, disorder of attention and cognition (Fick, Agostini & Inouye, 2002). Delirium superimposed on dementia is often not recognised and can lead to prolonged hospitalisation, decline in cognitive and physical functioning, institutionalisation, rehospitalisation and death (Fick et al.). Screening for dementia or delirium in ED is not routine at present despite research indicating an increased mortality risk in those patients who have delirium (Han et al., 2010, McCusker et al., 2002). Having a family caregiver present

to supplement the information supplied to staff should improve both accuracy of health history, and adherence to discharge instruction. Health professionals however must take the time to ask and to listen to family (Fick et al., 2002). Ignoring information provided by family caregivers appeared to jeopardise the care and treatment provided in ED and this was clearly a concern for participants.

Nursing focus on physical need rather than psychosocial needs is an indicator of the value nurses place on practical skills (Nystrom, Nydén & Petersson, 2003b). Being ignored was stressful for participants who strived to attain quality care for their loved ones. Doubts about the provision of adequate pain relief were expressed along with concern with restraint procedures that had the potential to compromise the PWAD. These practices could be interpreted as abusive. Difficulties between nurses and patients with dementia in acute care settings are identified in a study by Eriksson and Saveman, (2002). The study aimed to describe nurses experiences of difficulties related to caring for patients with dementia. Ricoeur's Interpretation theory was also used to analyse the findings. Patients with dementia were at risk of being neglected by nurses who were ill equipped to manage their needs in the ward. This led to neglect, due to being seen as low priority by nursing staff who valued contact with patients they had little difficulty communicating with, or who were perceived as being more severely unwell. Sedatives and/or hypnotics were used to control the behaviours of patients with dementia to allow nurses to meet the needs of their other patients. Sedating people with dementia has the risk of causing over sedation and anxiety (Eriksson & Saveman, 2002). Patients with dementia often have difficulty making their needs known, leading to frustration in nursing staff who failed to treat them with dignity. Lack of dignity violates integrity (Eriksson & Saveman, 2002). A participant in my study was concerned about the use of sedation on her husband in order to render him compliant for procedures. She felt sedation increased his risk of falling as he had had adverse effects from being sedated in the past.

Participants in my study were not included in care and did not negotiate with staff in contrast to a study by Allen (2000) who studied the negotiation between expert family caregivers and healthcare professionals in the acute hospital setting. In the Allen study ethnographical data are examined revealing the negotiation that took place between the expert informal

caregiver and nurses in a ward setting. The study concluded that expert informal caregivers pose a challenge to the fundamental features of the social organisation of nurses' work: nurse control over caring processes, their claim to expertise and their license to define standards of care (Allen). The opportunity for participants to negotiate with health professionals on matters of treatment and care for their loved ones was not available to participants in my study. Being ignored by healthcare professionals belittled the experience causing a reluctance to intervene in any way.

One participant reported multiple attendances at ED with her PWAD for the same gastrointestinal problems. This caused her immense distress as they were discharged with no solutions. If there was no diarrhoea seen in a specific time then the PWAD was discharged home. The participant resorted to looking up symptoms on the Internet as she felt staff were missing vital signs. In a study looking at repeat attendance to ED by older people (Bentley and Meyer, 2004) found most people in the over 75 age group that who re-attended had gastrointestinal disorders identified on a recent previous attendance. They stated that even when these older people were accompanied by family members, staff did not routinely explore concerns or validate issues or abilities with them. A more detailed assessment was recommended to include functional and psychosocial aspects rather than only medical. This mimics the experience of the aforementioned participant who was not given any information to assist her to manage the PWAD following discharge.

5.4 Being Abandoned

Being left alone for long periods of time was interpreted as being abandoned. The length of time participants spent waiting in the ED has also been noted in other studies (Gordon, Sheppard & Anaf., 2009; Nyström, et al., 2003a; Britten & Shaw.,1994; Nyström et al., 2003b, Nyden et al., 2003). Participants mentioned the need to monitor and maintain their loved ones during the wait. Nyström et al. (2003b) conducted a study using a life-world hermeneutic approach to identify factors that explain nurse-patient encounters with negative outcomes for patients. The study setting was ED and interviews were conducted with nursing staff and patients. Nurses were interviewed to obtain in-depth information about nurses' attitudes when encountering patients. Patients were interviewed about the lived experience

of encountering nurses in ED. Comparisons were made between nurse and patient views. Findings revealed similarities with findings in my study. Nursing interventions were fragmented and carried out according to a system similar to a conveyer belt in industry. Participants in my study discussed being processed and "*moved on like a cattle truck*" which caused distress and feelings of depersonalisation. Nyström et al. (2003a) also commented that older patients need to bring their next of kin to ED with them to mitigate many hours of waiting alone. They note that additionally the next of kin is forced by the system to take on the task of monitoring the patient and seeking help when needed. The participants in my study indicated this role caused them stress, especially when they could not locate staff to assist when they needed them. Participants acknowledged the stress that being in ED placed on them. Nursing staff may not be prepared to manage a family suffering from grief and/or stress due to lack of knowledge and insufficient preparation (Redley, 1996). A more holistic approach to nursing within the ED has been called for to work with families using nursing specific models rather than the current medical model. The medical model has been criticised as it adheres to the traditional loyalties where nurses perpetuate their role as an advocate for the physician rather than the patient (Byrne, 1995). There is also a culture identified in some research in ED where families have been considered a negative influence on delivery of healthcare. Family members have been described as demanding and interfering, placing added burden on the nurses' role. This is seen in situations of high intensity care such as resuscitation (Redley).

There was a perception that staff did not understand dementia and so tended to limit contact to necessary medical procedures only. This limiting of contact has been likened to a propensity for neglect if nurses avoid the complexity of caring for PWAD by reducing time spent with them (Borbasi, Jones, Lockwood & Emden, 2006). Though not directly mentioned by participants there may have been lack of contact due to ED staff having received relevant information prior to presentation for those PWAD transferred from residential care facilities by ambulance. Four of the six PWAD were transferred by ambulance from a residential care facility to the ED. Participants who accompanied them did not mention being present for the handover of information but remained with the PWAD during the ED stay. Only one participant mentioned their PWAD being accompanied by a

caregiver from the residential care facility. In this case the caregiver from the facility was the person most ED staff referred to when seeking information, with the participant being sent out to another part of the ED to wait.

Research on patients from residential care facilities in ED has focused on the need for improved primary care practices aimed at reducing transfers for non-urgent illness, rather than psychosocial needs of these people and their families while in the ED (Arendts, G. & Howard, K. 2007). One study found patients admitted from residential care facilities were disadvantaged in the ED due to a social construct within ED that denigrated their presence as being inappropriate (McClosky & van den Hoonaard, 2007). There is friction between residential care facility staff and ED staff that is well researched and alarmingly seen as “normal” (McClosky, 2011).

Participants in my study felt they could not safely leave their loved ones alone and it was distressing for them to have to try and attract the attention of staff when there was a problem or medical deterioration in their loved one.

Recent research using Bowlby’s attachment theory has uncovered the emotional meaning of behavioural responses to loss and abandonment for PWAD (de Vries & McChrystal, 2010). Bowlby’s attachment theory is described as: *a relationship between an attached person and an attachment figure in which the former seeks security from the latter under stressful circumstances.* (de Vries & McChrystal, 2010, pg.289)

This is of particular importance when considering the impact of being in an unfamiliar surrounding (such as ED), without a familiar figure (family member), in a stressful situation (illness or injury) for people with dementia. Looking specifically at people with Alzheimer’s Disease Meisen (1993) studied the behaviour of PWAD when their attachment figure left the room. Behaviours included, crying; looking after; running; and calling after the attachment or security figure. This clearly indicates the distress caused by removal of an attachment figure from the care of a PWAD. Participants in my study were asked to wait in another room, possibly to facilitate unhindered access to the PWAD. One participant was concerned about the need to sedate her relative in order to carry out procedures while she was asked to wait in another area. If she had been allowed to remain close-by

to give support and reassurance to the PWAD sedation may not have been required.

Being left alone with the PWAD was seen to be stressful to participants when they needed to leave the PWAD to access assistance. They could not attend to their own needs or those of their loved ones during this time. Leaving the PWAD alone was seen as being unsafe by participants.

5.5 Being processed

The core theme of being sidelined reflected the adherence to protocol and process rather than individualised care. This practice conflicts with person centred care that is advocated for people with dementia to maximise their ability to interact with and contribute to their care. Person centred care is described as the unique individuality and experience present in everyone and focuses on using this to plan interventions and care that is meaningful to each individual (Kitwood, 1997).

The ED in this study used a medical model of care and this caused conflict and frustration with participants who stated they did not see health professionals unless they were carrying out procedures for the PWAD. Process in the ED under study is linked directly to the medical model of diagnosis and treatment of physical problems. The process includes nurse triage, medical assessment, diagnostic procedures, and treatments based on results of investigations. The technical, or medical model, affects interaction between patients and care providers according to Mishler (1984) cited in Nyström, Nydén and Petersson (2003). Mishler indicates there are two voices in health and medical care: the *voice of medicine* and the *voice of lifeworld*. He said "... the *“voice of medicine”*, representing the technical-scientific assumptions of medicine, and the *“voice of the lifeworld”*, representing the natural attitude of everyday life." pg 26.

The feelings of being ignored and sidelined in my study resonate with the *voice of medicine*. Nurses are in a position to implement a more patient focused model of care that would address the lifeworld concerns of patients and their families but there appear to be barriers to this approach in the ED. Participants in this study felt they were *processed* through the department, but were not informed of the process. This is similar to the findings in a study by Cowdell (2010) who looked at the care of older people with

dementia in an acute hospital setting. She used an ethnographic approach and data were collected through observation and interviews with patients and nursing staff. Her conclusions were that there is an urgent need to develop innovative methods of practice that enable a rekindling of empathy in nursing and a move away from the current habitus (process or traditional method of working) to a more person-focused approach.

Participants were not informed of waiting times or the reason for the wait and therefore all perceived the wait to be long. The lengthy wait to be seen or to receive results caused stress to the participants who were concerned for their relative. Waiting for long periods without a meal was concerning for both the participant (who could not leave to find food or a drink) and the PWAD who was not offered anything to eat or drink. Participants felt unable to meet the basic needs of their loved ones during the long wait as they were not able to safely leave the PWAD alone. Older patients in the ED have been researched in relation to unsatisfied basic needs by Nydén et al. (2003). Their study used a life-world-based interpretive approach interviewing two women and five men aged between 65 and 88 years. The study concluded that attention to basic need satisfaction assists older patients to play an active role in their own health process when in ED. Triage must include attention to the social, psychological and functional status of each individual, defining barriers to active decision making by this group of older patients. They further concluded with a recommendation that it is important that older patients play a full part in the assessment process and make informed choices (Nydén et al., 2003).

The participants in my study felt they were acting as “surrogates” or advocates for their PWAD but this was not acknowledged by ED staff. Informed consent is a vital part of patient treatment in any healthcare environment. The issue of medical decision-making-capacity (DMC) is discussed by Larkin, Marco and Abbott. DMC is essential to the ability to make informed choice and in cases of uncertainty the assistance of a third party such as a surrogate, consultant or another clinician is valuable in informing the most appropriate action. In cases where DMC determination is challenging or ramifications of a decision are serious it becomes even more significant for health professionals to seek this second opinion (Larkin, et al.). Participants in my study were vague in their response to questions about consent for treatment, indicating it was not at the forefront

of thoughts on the experience. One participant who had multiple visits to ED felt accuracy of information seeking was dependent on the individual to whom you were speaking. It was not a standard response and seemed to be related to the integrity and thoroughness of each health professional at the time. The presence of a legal document such as a living will, advanced directive or a person holding enduring power of attorney makes decision making and consent easier for health professionals when there is concern about DMC (Larkin et al.). None of the participants in my study indicated they had Enduring Power of Attorney but this was not a question that was specifically asked, and is a study limitation.

5.4 Being Passive Observers

All participants reported incidences of lack of power in relationships with health professionals but none challenged this. From allowing procedures to be carried out on the PWAD that they had concerns about, to simply accepting being there to listen and do as you are told, there was uniform acceptance of whatever came their way. This sense of lack of control in the ED environment is confirmed in the literature and can be a response to negative staff attitudes toward family in ED.

In a study by Watson, Marshall, and Fosbinder (1999) of elderly patients' perception of care in the ED, "*personal tolerance*" emerged as understanding and patience among the sample group when one or more care expectations were not met by staff. Waiting for long periods of time was seen as being normal to allow people with perceived greater needs to be seen first.

Being passive observers reached a more significant level in my study whereby participants allowed procedures to be carried out on the PWAD that they perceived to be unnecessary or uncomfortable without complaint. This finding is more aligned to the behaviours of elderly patients in ED who try to be *good patients* to maintain good relationships with nurses (Nyström et al., 2003a). The participants in my study tended to avoid making contact with nursing staff as they perceived them to be too busy. In a further study by Nyström et al. (2003b) nursing activity (e.g., blood taking, cannulations, clinical observations and so on) appeared to be organised according to the instructions of medical staff and was well organised, but nurse caring goals

were obscure and not commonplace. Patients in the study did not feel safe to make their feelings known for fear of being seen as anything other than *good* patients.

The psychosocial needs of participants in my study were met predominantly by the Red Cross voluntary auxiliary team. This situation is significant as the needs of the family are not being met unless the auxiliary staff are present. Volunteer staff are not in ED all hours so it would be useful to capture what occurs in their absence.

5.5 Study limitations

- This study did not specify time of presentation to ED and this may affect the results. Traditionally triage is only available during daytime hours so presentations after hours would be assessed in the traditional manner of first come first served if *walking wounded*.
- Participants were not asked if they had Enduring Power of Attorney for their family member, this would have enriched the data and discussion.
- This study was a qualitative design and as such is not able to be generalised. It captured the lived experience of six family members of a PWAD in the ED but did not include experiences of healthcare professionals. A more in-depth result would have been possible if this had been included.
- Phenomenology seeks to find meaning in the lived experience of people and as such interpretations are made on subjective data. The experience of each person is unique to them. This study reports the findings from six participants. A larger sample group may have added to the depth of data.
- Advertising for participants in a local paper may have influenced the data collected for this study. Snowball sampling may have resulted in a broader range of participants.

5.6 Implications and recommendations for Practice

- Referral to effective intervention services can be difficult as many regions in New Zealand do not have these resources. If resources do exist, not all health care professionals are aware of them, so there is a need to provide information to facilitate access to services via appropriate referrals.

- Implementation of the Alzheimer's Society Dementia Strategies for acute settings particularly the education for healthcare professionals.
- Implementation of a patient focussed care model in acute care settings.
- Communication training with emphasis on the Developmental Model of Healthcare Communication (Northouse & Northouse, 1985).
- Introduction of a screening tool for dementia and delirium in the ED i.e. Mini -mental State Exam, (Folstein et al. 1975) Confusion Assessment Method (Inouye et al. 1990).
- Adjusting ED environment to meet the needs of people with dementia. This can be achieved by modelling an area specifically for dementia patients that is equipped with comfortable furniture and equipment to divert the attention away from the unfamiliar to the familiar. Signage that uses pictures to indicate where the toilets are located along with careful selection of colour to identify the area rather than the plain cream often used in all areas. Staffing this area with the same nursing staff will ensure a level of consistency is maintained that is easy for a person with dementia to assimilate. (Cunningham & McWilliam, 2006, Nethery, Allen & Arnold, 2010).

5.7 Recommendations for further research

- Further studies on the experience of family caregivers in ED would increase the body of knowledge in this area.
- Exploration of the emotive drivers of *being passive* for family caregivers in ED.
- The meaning of abandonment for family caregivers in healthcare settings.
- Power relationships between healthcare providers and family caregivers of older persons with AD in acute healthcare settings.
- Out of hours practice in ED – what happens when nurse triage is not available? What happens when auxiliary volunteer staff are not available?

- Factors that contribute to satisfaction for family caregivers of people with AD in ED.

6.0 Conclusion

The aim of this research was to give meaning to the experience of being a family caregiver when taking a loved one with dementia to ED. It was also to interpret and give meaning to this experience. Using a phenomenological hermeneutic method was the preferred option as this methodology studies essential meaning revealed in the interpretation of text. Further depth was achieved using Ricouer's interpretive theory where the researcher becomes an integral part of the interpretive process. It was impossible to separate the influence of my own experiences from the interpretation and indeed results would be incomplete if I had.

Findings reveal being sidelined in ED as a family member. In this manner participants were observing the game from the sideline rather than taking part in the play. Indicators of being sidelined were being ignored, being processed, being abandoned and becoming a passive observer. The most significant finding, not seen in other studies, was the acceptance of being a passive observer by family caregivers. The inability to express feelings of concern to healthcare professionals is revealing in itself and warrants further research into the reasons behind this. My personal learning was greatest in this area, and I found this aspect of the experience the most distressing. Not being able to express concerns impacts on the ability to advocate for a loved one, who either lacks capacity, or ability, to speak for themselves. This can lead to adverse outcomes for patients with AD in the ED.

The findings of this study have contributed to the body of knowledge in this area. Due to the paucity of lived experience study specific to family caregivers of people with AD in the ED results could only be compared to like results in research on older patients in this setting. Family caregiver experience could only be compared with research of family caregivers in the acute setting that included the ward setting as well as ED. More study is required to give healthcare professionals vital insight into perceptions of service delivery in ED.

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Appendix 1



Transcriber Confidentiality Agreement


Thank you for agreeing to transcribe the taped interview notes for Sandy Ridley's research.

This material is confidential and requires you to sign the confidentiality agreement below.

I understand that the material contained in the interview tapes is confidential. All transcripts will be forwarded electronically to Sandy Ridley. No copies of the transcripts will be made electronically or on paper.

Transcripts will be held electronically in a password protected file. Once the transcripts are sent on to the researcher the files will be deleted.

I will not discuss content of the transcripts and interviews with anyone other than the researcher.


..... Signature

4/7/10
..... Date

GRADUATE SCHOOL OF NURSING, MIDWIFERY AND HEALTH

Appendix 2



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone: (04) 496 2405
Fax: (04) 496 2191
Email: central_ethicscommittee@moh.govt.nz

14 April 2010

Ms Sandra Ridley
20 Otatara Road
Taradale
Napier 4112

Dear Ms Sandra Ridley

Ethics ref: CEN/09/52/EXP
Study title: Caregiver Experience of Registered Nurses Communication in Emergency Department - Insights from Family Caregivers of People with Alzheimer's Disease

The above study has been given ethical approval by the Central Regional Ethics Committee.

Approved Documents

- Consent Form, Version 2, FINAL, March 2010
- Information Sheet, Version 2 FINAL, March 2010
- Appendix 1: Caregivers Experience of Emergency Department Interview Schedule
- Advertisement
- Transcriber Confidentiality Agreement

Accreditation

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Final Report

The study is approved until 14 December 2010. A final report is required at the end of the study and a form to assist with this is available at <http://www.ethicscommittees.health.govt.nz>. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Amendments

It is also a condition of approval that the Committee is advised of any adverse events, if the study does not commence, or the study is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.



Central Regional Ethics Committee

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone: (04) 496 2405
Fax: (04) 496 2191
Email: central_ethicscommittee@moh.govt.nz

1 June 2010

Ms Sandra Ridley
20 Otatara Road
Taradale
Napier 4112

Dear Ms Sandra Ridley

Re: Ethics ref: **CEN/09/52/EXP** (please quote in all correspondence)
Study title: Caregiver experience of registered nurses communication in
Emergency Department - insights from family caregivers of people
with Alzheimer's Disease

The Central Regional Ethics Committee considered and approved an amendment to your study on 20/04/2010.

Approved Documents

- Public Notice : "Do you care if a family member with Alzheimers Disease?", received 14 April 2010.

Please don't hesitate to contact me for further information. The Committee wishes you well with your study.

Yours sincerely,


Sonia Scott
Administrator
Central Regional
Email: sonia_scott@moh.govt.nz

Appendix 3



INFORMATION SHEET

Study title: Caregiver Satisfaction with Registered Nurse Communication in the Emergency Department – Insights from family caregivers of people with Alzheimers Disease.

Principal investigator: Sandra Ridley RGON,BN

Master of Nursing - Applied (student)

20 Otatara Rd, Taradale, Napier 4112

Ph: 06) 845 1512

Supervisor: Dr Salomé Meyer

PhD(CIE), MEd(CAE), BCur letA(Hons)(Adv. NE), BCur

letA(NE), RN

Senior Lecturer

Graduate School of Nursing, Midwifery & Health,

Victoria University of Wellington

PO Box 600, Wellington

New Zealand

Introduction

You are invited to take part in a study of family caregiver experience of Registered Nurses communication in the Emergency Department. The study is designed to explore and describe the experience you as a caregiver had when you accompanied your family member to the Emergency Department of a public hospital. The study looks especially at your experience communicating with Registered Nurses in the Emergency Department. Results will help inform nurses of your needs when bringing a loved one who has Alzheimers Disease to the Emergency Department.

The Emergency Department can be a challenging environment for people with Alzheimers disease due to noise, multiple personnel, and unfamiliar environment. Often tests and procedures are undertaken and periods of time are spent waiting for results. As a family carer it can be difficult to find out what is happening at various times and so good communication becomes an essential aspect of this process. This study is designed to elicit what type of communication you received from Registered Nurses and if this was satisfactory for your needs. Your relative may have been admitted into the hospital for treatment or they may have been discharged home. How did you know what was happening?

The researcher will ask a set of broad questions to each participant to explore your experience. Data from each interview will be examined for common themes. It is anticipated that the results of this study will be published in a nursing journal.

This study is part of the requirements for achieving a Master of Nursing and will be presented as a thesis. The thesis will be held at Victoria University and be available to other post-graduate students on request. It is anticipated that the results of this study will be published in a Nursing Journal. The study may also be presented by Sandra to an audience of health professionals at relevant Conferences.

Participation

Your participation is entirely voluntary (your choice). If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason.

Participants are being selected via newspaper advertisement, through information being available at Alzheimers Society branches, and carer support groups run by the District Health Board. It is anticipated that Sandra will interview from 6-10 participants. The time span to conduct this study is twelve months. Interviews will occur throughout March/April 2010.

Participation will involve being interviewed by the researcher (Sandra Ridley). It is anticipated the interview will take no longer than one hour and will be tape recorded. Sandra can interview you either at your home or at a mutually agreed destination that is quiet and private. You do not have to answer all the questions, and you may stop the interview at any time.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

Interviews will be transcribed (put in writing) for analysis. All tapes and transcriptions will be kept in a secure location by the researcher eg. locked filing cabinet. Electronic transcription records will be kept on a password protected computer.

Confidentiality

No material that could personally identify you will be used in any reports on this study. You will be asked to provide a pseudonym or false name as a means of identifying your interview from that of other participants. A false name will also be required for your relative if you refer to your relative during the interview (in order to protect their identity).

General

If you wish to have an interpreter present for the interview this can be arranged. Please indicate on the consent form.

If you require any further information about this study please contact Sandra on the phone number listed on page one of this information form.

CONSENT FORM

Request for interpreter (circle your response)

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	loe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	loe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai
	<i>Other languages to be added following consultation with relevant communities.</i>		

- 1 I have read and I understand the information sheet dated March 2010 for volunteers taking part in the study designed to describe my experience of Registered Nurses communication in the emergency department. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

- 2 I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.
- 3 I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future health care.
- 4 I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.
- 5 I have had time to consider whether to take part in the study.
- 6 I know who to contact if I have any questions about the study in general.

8 I consent to my interview being audiotaped/videotaped.

Yes

	N
	o

9 I would like the researcher to discuss the outcomes of the study with me'.

Yes

	N
	o

1 I agree to my GP or other current provider being informed of my participation in
0 this study/the results of my participation in this study.

Yes

	N
	o

I (full name) hereby
consent to take part in this study.

Date:

Signature:

Full names of researchers:

Contact phone number for researchers:

Project explained by:

Project role:

Signature:

Date:

