



# Forget Me Not

*A Study of Public Health Nurses and  
informal Carers of People with  
Dementia and Alzheimer's  
in Co. Galway*

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This study is dedicated to Maura Kelly and Betty Gal



## **Executive Summary**

Dementia is an umbrella term used to describe a collection of symptoms characterised by the loss of cognitive and social functioning and behavioural changes (Bayer, 2006). It is caused by many different diseases, of which by far the most common is Alzheimer's disease. Dementia/Alzheimer's is a progressive, debilitating condition with increasing prevalence and complex needs. There are an estimated 30,000 people with Dementia in Ireland. (O'Shea & O'Reilly, 1999) The number of patients with Dementia is estimated to double over the next fifty years (Byrne, et al., 2006). The challenges presented by the increasing public health and social impact of caring for people with Dementia has become clear in recent years (North Eastern Health Board, 2003). Although a significant number of studies have been undertaken and have assessed carers of persons with Dementia/Alzheimer's, no study has been carried out in a Public Health Nurse context in the west of Ireland.

The purpose of this research was to evaluate the Public Health Nurse (PHN) areas to identify the number of clients in County Galway with Dementia/Alzheimers; to identify the stage of the dementia, and to identify the common referral sources to the Public Health Nurse service. The second phase of the study was conducted with informal carers of the clients with Alzheimer's/Dementia. The purpose of this component of the study was to examine the characteristics of caring, such as the duration of caring role the services accessed by the care recipient, and to identify any deficits in support services for both the carer and the care recipient.

To achieve this, the authors devised two questionnaires; one for Public Health Nurses in County Galway (93% response rate), and the second questionnaire for carers identified by the Public Health Nurses (69% response rate).

**The findings revealed that:**

- The greatest support to the carers of the person with Dementia/Alzheimer's is the Public Health Nurse.
- The highest source of referral to the Public Health Nurse, is the family.
- Public Health Nurse areas in east Galway had a significantly higher percentage of people with Dementia/Alzheimer's on their case load.
- The highest percentage of patients with Stage 2 Dementia/Alzheimer's is living in the community.
- 62% of people with Dementia/Alzheimer's live in a rural area and 82% of these people are cared for by family members.
- The mean number of years that carers were caring for the person with Dementia/Alzheimer's was six, with 9% caring for over 12 years.
- 66% of carers were caring over 150 hours per week, with 91% of carers caring for the person with Dementia/Alzheimer's for 7 days a week.
- 94% of carers stated that the Public Health Nurse is the service that they rely on most followed by the General Practitioner.
- 55% of carers did not have a day care service or any information regarding a day care service in their area.

- 30% of carers stated that they received all the services that they needed.  
Conversely, 34% of carers stated that they did not receive all the services that they needed, of which, 41% required more home help, 37% requested coordination of services, and 16% requested a specialist Public Health Nurse.
- 3% of carers received information on counselling, 12% received information on occupational therapy and 3% received information on reminiscence therapy.

**Recommendations for Public Health Nurses include:**

- Appointment of a specialist Public Health Nurse;
- Implementation of a research tool to aid in early diagnoses of Dementia/Alzheimer's
- On-going education of Public Health Nurses.

**Recommendations for Carers include:**

- The development of a National Carers Register;
- The provision of an adequate range of Carers Support Services;
- The development of a Carers Needs Assessment protocol;
- Education and Training for carers;
- The expansion of the range and availability of services such as Respite, Day Care, Counselling and Support Group Services.
- Finally, further research is required to determine whether interventions designed to increase caregiver support would decrease hospital admissions and institutionalisation among older people.

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## **Introduction**

There are an estimated 30,000 people with dementia in Ireland (O'Shea & O'Reilly 1999). It is suggested in the literature that this number will increase along with the ageing of the Irish population in the twenty-first century (National Council on Ageing and Older People 1999).

Dementia is an umbrella term used to describe a collection of symptoms characterised by the loss of cognitive and social functioning and behavioural changes (Bayer, 2006). Dementia is a progressive irreversible illness characterized by widespread impairment of mental function which may include memory loss, language impairment, disorientation, personality change, difficulties with activities of daily living, self neglect and psychiatric syndromes (National Institute for Health and Clinical Excellence 2006). Dementia is caused by many different diseases of which by far the most common is Alzheimer's disease. It is essential therefore to identify the needs of persons with Dementia/Alzheimer's and the needs of their carers in order to plan and to make available the appropriate services and supports.

The challenges presented by the increasing public health and social impact of caring for people with Dementia has become clear in recent years (North Eastern Health Board, 2003). Research has identified that, while there are positive and negative elements to the caring role, carers are at a higher risk of stress and mental health problems and that the burden of caring has social, economic and health based elements. In Australia, O'Connell et al (2003) highlighted that carers are unable to participate in social and

health related types of activities, due to the burden of care. Irish research conducted so far has shown that caring for an individual in the home can have a negative impact on the family carer's mental, emotional and physical health, with high levels of burden (O'Brien, 2008; Care Alliance Ireland, 2008; O'Connor and Ruddle, 1998; Blackwell et al, 1992). Co-resident carers, especially spouses, are of primary importance in maintaining people with Dementia/Alzheimer's in their own homes in the community rather than in long term residential units which may be more costly and have greater environmental poverty (Schneider, et al 1999).

In a study of policy and practices for dementia care in Ireland O'Shea, (1999) acknowledged that responsibility of the person with dementia and their carer falls on the Public Health Nurse. O'Shea (1999) states that the Public Health Nurse does not have the time or the special training to provide the optimal care for the person with Dementia living at home. Although a significant number of studies have been undertaken and have explored carers of persons with Dementia/Alzheimer's no study has been carried out in a Public Health Nurse context in the west of Ireland. In a recent Irish survey of General Practitioners it emerged that there was an absence of adequate and community care services for families when a relative is diagnosed with dementia (Cahill & Clarke, 2002).

### **Purpose of Study**

The first phase of this study was an evaluation of the Public Health Nursing areas to identify the number of clients in County Galway with Dementia/Alzheimer's; to identify the stage of the dementia, and to identify the common referral sources to the Public

Health Nurse Service. The second phase of the study was conducted with informal carers of the clients with Alzheimer's/Dementia. The purpose of this component of the study was to examine the characteristics of caring, such as the duration of caring role; the services accessed by the care recipient, and to identify any deficits in support services for both the carer and the care recipient.

### **Aim of Study**

The aim of this research is to set out a care pathway for the person with Dementia/Alzheimer's that enhances their rights to care and support services that allow them to reach their potential within the confines of their condition (O'Shea, 1999).

## **Chapter 1**

### **Literature Review**

#### **Introduction**

Dementia is an umbrella term used to describe a collection of symptom characterised by the loss of cognitive and social functioning and behavioural changes (Bayer, 2006). Dementia is a progressive irreversible illness characterized by widespread impairment of mental function which may include memory loss, language impairment, disorientation, personality change, difficulties with activities of daily living, self neglect and psychiatric syndromes (National Institute for Health and Clinical Excellence, 2006). It is caused by many different diseases of which by far the most common is Alzheimer's disease.

A carer has been defined as: “Someone who provides assistance on an unpaid basis to one or more family members, relatives, friends or neighbours, who have difficulties in looking after themselves or in undertaking daily activities because of disability, age or long-standing illness” (Cullen et al, 2004). The Census of 2002 which included an item on caring for the first time, and more recently the Census of 2006, has defined a carer as: “Someone who provides regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability” (Central Statistics Office, 2007).

Over the decades, a large body of research has documented the importance of the family in the lives of both the healthy and impaired community-dwelling elderly (O’Shea, 1999, McKinley et al, 1995, Horowitz 1985). When serious deficiencies in health occur, family care-giving emerges as a pivotal concern. (O’Shea 1999). However, as the research

reveals, family care giving is not a role or activity that individuals typically desire, seek or expect.

The Census 2006 found that there are a total of 160,917 carers aged 15+ years in Ireland (an increase from 148,754 carers evidenced in the Census 2002), thus constituting a prevalence of 4.8% of the total Irish population (Central Statistics Office, 2007). Of this total, 62% are female (100,214 carers), and 38% are male (60,703 carers). The duration of care provision ranges from 1 to 14 hours per week which is carried out by 93,363 (58%) carers; 15 to 28 hours per week which is carried out by 17,093 carers (11%); 29 to 42 hours per week which is carried out by 9,578 carers (6%); to 43 hours and over which is carried out by 40, 883 carers (25%). This would mean that between 2,385,489 hours and 9,056,306 hours of informal care is provided each week in Ireland.

The 2006 Census data also found that there was a total of 9,252 carers aged 15-plus years residing in Galway (an increase from 8,362 carers evidenced in the census 2002), of which, 2,409 carers resided in Galway City, and 6,843 carers resided in Galway County. Of this total for Galway, 61% are female (5,611 carers), and 39% are male (3,641 carers) (Central Statistics Office, 2007). The duration of care provision for Galway carers ranges from 1 to 14 hours per week which is carried out by 5,321 carers (58%); 15 to 28 hours per week which is carried out by 960 carers (10%); 29 to 42 hours per week which is carried out by 614 carers (7%); to 43 hours and over which is carried out by 2,357 carers (25%). This would mean that between 138,878 hours and 523,138 hours of informal care is provided each week in Galway.

The findings of the Western Health Board's strategy for 2001-2006 revealed that the population of the Western Health board is predisposed to providing care for older people in their homes and communities with an estimated 19,317 carers in the Western Health Board region. This strategy also illustrates the profound physical, emotional, social and financial effects on providing constant care on a long term basis (Western Health Board, 2001).

### **Public Health Nurses and Carers**

For years Public Health Nurses have recognised that 'Community' Care is usually 'family care' and that the family is the primary unit of health care. As health professionals, Public Health Nurses are legally liable and morally responsible for the quality of the care they provide to patients (Gunther, 2002). Public Health Nurses who work closely with patients/carers of people with Dementia/Alzheimer's require a theory base that helps them to understand how to approach families in their home, how to assess potential and actual health concerns from a family perspective, and how to intervene most effectively with families to prevent and manage health concerns with Alzheimer's and Dementia (Krisjanson & Chalmers, 1991).

The Years Ahead (Department of Health, 1988) identified a significant gap between patient and carer needs and existing service provision in the area of dementia.

Unfortunately, this gap has not been significantly bridged in the past ten years and services remain undeveloped (O'Shea & O'Reilly 1999). It has been recognised that of particular importance in supporting the health and social well-being of older carers and

their dependents is the development of health promotion programmes (The Carnegie Inquiry, 1993). This Inquiry suggests that these programmes need to be applied in association with policies affecting environmental factors, housing, security, social cohesion and inclusion, accident prevention and positive mental health. Carers have indicated that they are neither given sufficient information from health services staff about the personal and social consequences of medical conditions, nor are they routinely signposted to other sources of information and support (Banks, 1999). These findings are highlighted in other research studies.

The survey of carer's experiences of the NHS by the Carers National Association (Henwood, 1998) found that only 11% of carers reported that they had been given any information, which would enable them to care more safely. The Princess Royal Trust for Carers Study (Warner, 1998) also found that carers are not given the right help and information to carry out the medical procedures, which they routinely undertake. A study of carers views on hospital discharge arrangements showed carers were concerned about the limited and partial information provided (Arskey, 1997). In addition, carers from black and minority ethnic communities have identified major difficulties in finding out about services and support (Katbamna, 1998).

O' Neill and Evans (1999) in a study in the West of Ireland identified that training, advice and support to care were major needs of carers. Sheridan et al (2003) conducted a study in the former North Eastern Health Board and found that less than 10% of carers who were caring for people with dementia reported receiving training to assist them in their caring role. Where training was required, carers requested that it focus on the actual

condition of dementia, basic handling, lifting and caring skills, as well as training the carer how to deal with behavioural difficulties and stress (Sheridan et al, 2003). Carers are often expected to carry out medical procedures and caring tasks with inadequate information or advice as to how to undertake these, how best to use equipment and what to do if problems arise. Assumptions are made about the knowledge or experience of the carer and information is not actively offered, leaving carers uncertain about what to ask and who to approach for advice (Banks and Cheeseman, 1999). Robinson and Yates (1994) found that carers who participated in a care giver training programme experienced a decrease in objective burden and a more positive attitude toward asking for help and using adult day care. Positive outcomes of training for family carers have been found in other research (Jansson et al, 1998; Mittelman et al, 1996). In relation to training for carers of people with Dementia, Gormley (2000) and Coen, et al (1999), concur that the efficacy of group-based education approaches to the management of behaviour disturbance is limited and more individually tailored interventions may be more appropriate. Ostwald et al (1999) found that interventions from a Carers Support Group, a Community Psychiatric Nurse or a Social Work Service for the carer on how to deal with negative behaviour associated with dementia, was helpful for carers on understanding how to prompt and communicate effectively, and how best to interact with the patient. Similarly, Pusey and Richards (2001) also advocated that problem-solving and behaviour management was effective in supporting carers of people with dementia.

## **The Impact of Caring on the Carer's Health**

The role of the family caregiver is often unexpected, but when confronted with a need for care and a sense of family obligations many wives, husbands, daughters and sons step forward to become caregivers. To facilitate and promote continued family care, Public Health Nurses and other members of the primary care team must emphasise the caregiver's health status and needs. Studies have shown higher depression levels and negative mental health among caregivers, Clipp & George, (1990). In a longitudinal study, McKinsley, et al., (1995) reported that caregiving exerted its greatest impact on the personal life of the caregiver (sleep, leisure, health and privacy) (61%) in comparison to family life (18%) and employment (15% to 20%). It is well recognised that caring for an older person or a person with a disability, often places social, emotional physical and financial pressures on the carer (McConaghy and Caltabiano, 2005; Visser-Meily, 2004; Given and Given, 1991; Klein, 1989; George and Gwyther, 1986; Poulshock and Deimling, 1984).

UK and Irish surveys highlight the large number of carers who are aged themselves, and who are unable to continue in the caring role due to poor health (Walker, 1993; Blackwell et al, 1992). O'Connor and Ruddle (1998) found that 68% of the carers in their Irish study reported that they had suffered from some chronic health problem themselves, with 24% reporting being in poor health and almost one-third believed that their health had suffered due to the demands of caring and emotional strain was found as having the most evident impact on carers. Collins and Jones (1997) suggest that carers, particularly spouses of frail older people at home, experience considerable psychological distress. The findings of the study by Collins and Jones (1997) suggests the need for greater

collaboration between formal and informal care, which supports the findings of an earlier Irish study by Blackwell et al (1992). Blackwell et al's (1992) Irish study further found that in terms of the specific strains associated with caring, the most frequently cited were the experience of caring as confining (65%) and the physical efforts required (46%).

A common theme throughout the literature pertaining to carers was a sense of loneliness and isolation, linked with anxiety and depression in the lives of caregivers (Banks and Cheeseman, 1999; Zarit et al, 1999; Collins and Jones, 1997). The totality of the caring role, and the overwhelming effect this has on carers' lives was demonstrated in a study of informal caring in Northern Ireland. For many, caring constituted more than a full-time job with most carers spending more than 40 hours per week caring (DHSS, 1996). Research undertaken in the former Western Health Board in Ireland found similar results. The majority of carers (59%) spent more time as a carer than they would in most full-time jobs (more than 40 hours per week), and 40% of the carers spent more than 80 hours per week providing care. One in ten carers spent every hour of the week looking after the person they were caring for (O'Neill and Evans, 1999). More recently, Harrison (2007) in an evaluation of the Home Care Package Scheme in a community care area in the west of Ireland found that the mean number of hours per week of informal care being provided to home care package recipients was 113.76, and over one-third of the informal carers (39%; n=15) were providing 168 hours of informal care per week.

Clipp and George (1990) compared spousal caregivers of dementia patients with spousal caregivers of cancer patients. They found that the caregivers of dementia patients had more compromised health than the carers of cancer patients. Clipp and George (1990)

found that caregivers were a group at high risk of exhaustion, depressed appetite, sleeping difficulties and nervousness. Farran, et al. (1993) found that certain disruptive behaviours were very distressing to caregivers. Gaugler, et al. (2000) in examining the impact of problematic behaviour with care recipients found that increases in problematic behaviour were most likely to increase stress level in carers emphasising the long term impact of problem behaviours on carer's emotional wellbeing.

All aspects of a relationship are affected by dementia (Wright 1991). O'Shea (2000) documents that over 85% of caregivers who participated in his survey reported adjustment for the family as a result of caring. Ruddle & O'Connors (1993) stated that the main impact of caring on family life was that the family as a whole could no longer participate in family activities and that all available time was consumed with caring for the person with dementia. Caring for a demented spouse/parent is a demanding task. The care situation is ambiguous and constantly changing especially when dementia is emerging and a number of unanswered questions and uncertainties can arise. A great number of studies have investigated the nature of burden associated with care giving and how coping strategies, social support and professional interventions may ease the burden. However the research does not reveal any clear conclusions. Individuals differ in the way they experience burdens, how they cope and what kind of interventions from which they benefit. Due to the gradual loss of meaningful mutual contact, uncertainties can arise (Wright, 1991). A good relationship may ease coping however as Dinjinslee (1992) acknowledges a good past relationship may strengthen the motivation to care, but may also interfere with successful coping. The caregiver may ignore his own needs and

become involved in a symbiotic relationship where the dementing process is hard to accept (Dinjinslee, 1992).

For care giving spouses/children the process of mental deterioration implies a gradual loss of meaningful interaction. Common themes in a dementia process are loss of predictability, continuity and meaningful interaction (O'Shea 1999). For Public Health Nurses, it is a challenge to help care-giving spouses/children find their best balance between closeness and distance in the caring relationship. Training in communication skills may be helpful in the process of differentiating the view points and needs of the couple. However, as the research suggests, information about dementia and educational approaches are not enough to help the care givers (Del Maestro, 1990).

### **Effective Support Services for Carers**

Dementia does not only affect the patients who suffer from it. It also imposes a significant burden on carers, causing stress, chronic fatigue, depression and irritability. This burden can be so great that the caregiver eventually gives up and becomes incapable of providing the required level of care, and the patient must be institutionalised and in many cases, this situation is preceded by an endless series of hospital visits (Gort et al, 2007). From a review of the literature it is evident that amongst the population of informal carers, many suffer from different forms of morbidity. By providing carers with an assessment of needs and monitoring carers stress, interventions can be provided to reduce physical and mental health decline in this cohort (Hoskins et al, 2005). Sperlinger and Furst (1994) argue that for this client group old age psychiatric services offer the best service model. Hoskins et al (2005) used a time series design over a two-year period in

Wales to evaluate the effectiveness of interventions provided by a Community Mental Health Team in reducing stress in carers of individuals with dementia. Using the Caregiver Strain Index (CSI) (Robinson, 1983), the authors found that one intervention made a significant improvement on the stress levels of carers, namely respite care. The authors state that the CSI could serve as a practical function in identifying high levels of stress occurring in carers over a period of time, so that they could be targeted for assistance in their own right (Hoskins et al, 2005). There are various scales for measuring the burden of caregivers. Gort et al (2007) used the Zarit scale (ZS) (Zarit et al, 1980) for assessing caregiver burden and collapse in caregiving at home in patients with dementia, and found it was an effective instrument for identifying caregiver burden but it also predicted relative collapse in caregiving at home, which was accompanied by an increase in hospital visits or institutionalisation. Moderate evidence of respite care in relieving carer's burden has been found in other studies (Knight et al, 1993). Palmer (1999) asserts that specialist teams (such as Community Mental Health Teams), can provide tailored care by assessing each dementia sufferer and carers needs individually in terms of mental, physical and social functioning.

Mittelman, et al., (1996) advocated that providing information and counselling can reduce stress in carers. Similarly, Mittelman et al., (1996) conducted a longitudinal study in New York with spousal caregivers who were provided with sessions of individual and family counselling that were task-oriented. These sessions promoted communication among family members, taught techniques for problem solving and patient behaviour management. It was found that patients who participated in the treatment remained cared for at home for significantly longer than those in the control group.

It has been recognised that of particular importance in supporting the health and social well-being of older carers and their dependents is the development of health promotion programmes (The Carnegie Inquiry, 1993). The Inquiry suggests that these programmes need to be applied in association with policies affecting environmental factors, housing, security, social cohesion and inclusion, accident prevention and positive mental health. Carers have indicated that they are neither given sufficient information from health services staff about the personal and social consequences of medical conditions, nor are they routinely signposted to other sources of information and support (Banks, 1999). These findings are highlighted in other research studies. The survey of carers experiences of the NHS by the Carers National Association (Henwood, 1998) found that only 11% of carers reported that they had been given any information, which would enable them to care more safely. The Princess Royal Trust for Carers Study (Warner, 1998) also found that carers are not given the right help and information to carry out the medical procedures, which they routinely undertake. A study of carers views on hospital discharge arrangements showed carers were concerned about the limited and partial information provided (Arskey, 1997). In addition, carers from black and minority ethnic communities have identified major difficulties in finding out about services and support (Katbamna, 1998).

Zarit et al., (1999) who undertook a major evaluation involving day care for patients with dementia, found that adequate amounts of day care reduced stress indicators among carers compared with a control group not receiving the care. Similarly, Gort et al., (2007) found that there was a tendency for there to be a greater caregiver burden and a higher

collapse in caregiving at home when the patient with dementia did not use a day centre. The authors recommend the provision of carers support programmes, including information and training for carers (especially relating to the management of patient symptoms and behaviour), respite breaks for carers, day centres, and telephone support for help with specific problems (Gort et al., 2007).

Essentially, irrespective of the intervention utilised, working together and involving the patient, carer, professional and voluntary organisations is indeed the way forward in caring for people with dementia and supporting their informal carers (Adams, 1997). Ultimately, such support services for carers will facilitate in providing more appropriate support to carers, and will avoid the need for unnecessary patient hospitalisation and thereby postpone for as long as possible the definitive institutionalisation of the patient. Although ‘The Years Ahead Report’ (NCAOP, 1988) made a number of recommendations in relation to the provision of services for informal carers, evidence shows that community support services for people with dementia and their carers in Ireland are still underdeveloped and fragmented (O’Shea and O’Reilly, 1999).

## **Conclusion**

There is little doubt that Public Health Nursing is a complex activity which requires a multi-faceted approach in responding to the changing needs of individuals with Dementia/Alzheimer's.

In order to meet the needs of patients receiving nursing care, Public Health Nurses need a professional education which provides profound and comprehensive knowledge, the ability to think critically and analytically and to have strong professional ethics.

McCormack, et al., (1999) suggests that helping the client with Dementia/Alzheimer's becomes easier if the Public Health Nurse is able to perceive different entities, if she has a holistic concept of the disease, if he/she is able to view health and illness as a continuum and if she can consider the various life situations experienced by the patient and his/her family and understands him/her as a member of a family and society.

Peplau (1988) is concerned with the 'total growth' of the patient's personality and her concept of the person has a holistic character. Peplau (1988) defines the person as an autonomous and rational being who aims to achieve certain goals in life. For the person with Dementia/Alzheimer's this includes, as Peplau suggests, fostering the relational dimension of patients which takes the form of supporting them in their contacts with families, friends and community at large. Peplau has made a clear ethical choice by placing relations at the centre of nursing. She presents a balanced picture of the patient, which emphasises autonomy and self-realisation, but also regards fellowship as an

essential aspect of being human, (Gastmans 1998). Peplau's vision for nursing is essential in the care of the person with Dementia/Alzheimer's in the community. For the Public Health Nurse in the community, knowing the patient with Dementia/Alzheimer's and their family is central to the ethics of care and responsibility (Benner, et al., 1985). This engaged knowledge of the patient and their family demonstrates that every person with Dementia/Alzheimer's is an individual and that the person with Dementia/Alzheimer's has the same human value as anyone else, the same rights as other Irish citizens, and the right to a fair and equitable health service (O'Shea, 1999).

## **Chapter 2**

### **Methodology**

#### **Introduction**

Nursing research is essential for the development of scientific knowledge that enables nurses to provide evidence-based health care (LoBiondo-Wood & Harper, 2002). A profession seeking to improve the practice of its members and to enhance its professional stature strives for the continual development of a relevant body of knowledge (An Bord Altranais, 2000). Nursing research represents a critical tool for the nursing profession to acquire such knowledge (Polit & Hungler, 2001).

This chapter outlines the research methodologies used in this study. The purpose of this study is to assess the person with Dementia/Alzheimer's, the carer and the services provided. The quantitative methodology selected in this study is a descriptive survey method.

#### **Research Approaches: Quantitative Approach**

According to Proctor (1998), individuals rarely take time to reflect in everyday life, but exploring basic personal beliefs could assist in understanding wider philosophical issues, notably the interrelationship between ontological (what is the nature of reality), epistemological (what can be known) and methodological (how the researcher can discover what he/she believes can be known) (Proctor, 1998). The philosophical level of a research method relates to its assumptions based on the most general features of the world encompassing such aspects as the mind, matter, reality, reason, truth and nature of

knowledge (Hughes, 1994). Proctor (1998) considers that consistency between the aim of a research study, the research questions, the chosen methods and the personal philosophy of the researcher is the essential underpinning and rationale for any research project. However, a major criticism for the positivist approach is that it does not provide the means to examine human beings and their behaviours in an in-depth way (Parahoo, 1997). Positivism adopts a clear quantitative approach, which aims to describe and explore in-depth phenomena from a quantitative perspective.

Due to the fact that carers of persons with Dementia/Alzheimer's may be vulnerable, it was decided, for ethical purposes, not to use observation as a method of data collection. A questionnaire was developed specifically for this study by a Public Health Nurse, an Assistant Director Public Health Nurse, a senior researcher and a regional care coordinator.

### **Methods of Data Collection**

This section will set out the research plan, designing the sample, the ethical issues for consideration, data collection and data analysis.

There is good evidence that well-designed questionnaires can be useful not only for measuring the views of clients, but also in contributing to quality improvement (Polit and Hungler, 1995).

By reviewing the literature the researchers decided that the most effective method of data collection would be to administer a questionnaire.

## **Questionnaire Design**

The researchers decided that two questionnaires should be devised one for the Public Health Nurses in County Galway (n = 65) and a second questionnaire for carers identified by the Public Health Nurses. One of the most efficient methods of collecting information from large numbers of people within a short period of time is the postal questionnaire (McDonnell, et al., 1998).

In the carers' questionnaire, there were three sections. The first section was about the carer and included the demographic of the person with Dementia/Alzheimer's. The second section concerned the person with Dementia/Alzheimer's and the third section was vital as it examined services available to the person with Dementia/Alzheimer's and their carers. The validity and reliability of the data collected depends on the design of the questions, the structure and the region of pilot testing (Oppenheim, 1992). These factors were considered and maximised by the researchers with careful attention to the following:

- The design of individual questions
- The layout of the questionnaire form
- The explanation of the questionnaire's purpose
- Pre-testing and cognitive interviewing
- Validity and reliability of instrument

## **Pre-Testing and Cognitive Interviewing**

The pilot site for cognitive interviewing was chosen in the community and consisted of three carers of dependent older people that were identified with the assistance of the

Carers Department, PCCC Services, Galway. These carers came from three distinct geographical areas, (Ballinasloe, Moycullen and Tuam). These carers were not included in the study. Cognitive interviewing is an amalgamation of cognitive psychology and survey methodology in the identification of questions that may elicit response error (Drennan, 2003). The overall aim is to use cognitive theory to understand how respondents perceive and interpret questions and to identify potential problems that may arise in prospective survey questionnaires. This process involves analysis of respondents' verbal reports during the pre-testing phase of the questionnaires prior to distribution and use in the main data collection stage (Conrad, et al., 1999; Dillman, 2000). The researchers carried out a retrospective interview after the carers examined the draft questionnaire as recommended by Drennan (2003).

These carers were asked whether they understood the questions, had they any difficulty with the questions and how relevant they felt the questions were. It was noted by the author that the carers involved in the cognitive interviewing had no problem with the length or structure of the questionnaire. Completion time of the questionnaire was measured and took approximately ten minutes.

### **Validity**

For questionnaires to be of use to practitioners, they have to produce valid and reliable data (Parahoo, 1997). The validity of a questionnaire is the extent to which it addresses the research question (Polit & Hungler, 1995). The questionnaire was piloted with a sample of carers and Public Health Nurses. Relevant focus groups were run by the

researchers to check opinions on the ease of completion. The questionnaires were modified according to the feedback received.

### **Content Validity**

Specific guidelines can and should be applied to the selection of experts for content validity determination. Lynn (1986) recommends a maximum of five experts. The researcher selected five experts: one Assistant Director of Public Health Nursing and four Public Health Nurses with an average of over ten years experience in public health nursing.

The expert panel of Public Health Nurses judged each item using a four-point ordinal rating scale. The content validity index was used to determine content validity (Lynn, 1986). The experts were asked, as part of the content validity assessment, to identify areas of omission and to suggest areas of possible improvement or modification (Lynn, 1986). The experts were asked to rate the relevance of each item in the questionnaire on a scale from one to four and the relevance of the entire instrument on a scale from one to four; 1 – not relevant, 2 – somewhat relevant, 3 – quite relevant, but needs minor adjustment, 4 - relevant. The content validity index is the proportion of items that received a rating of 3 or 4 by the experts. The content validity index for this questionnaire was 100%, as all items received a rating of 4 from the experts. The recommended changes were then made to the questionnaire. Oppenheim (1992) cautions on the use of ‘experts’ to pre-test a questionnaire as their interpretation of a question may be completely different from the intended participants’. The development of the questionnaire involved a rigorous consultative process with a Senior Researcher,

Department of Public Health, HSE West, Galway and with the Co-ordinator, Carers Department, Galway PCCC.

### **Reliability: Selection Procedure**

As the geographical area for this study included the County of Galway, it was decided to select all people with Dementia/Alzheimer's known to Public Health Nurses in Galway City and County (n = 144) . The key elements for deciding adequate sample size, other than resources and time constraints, include the size of the population to be studied, the likely response rate and the composition of the analysis to be achieved. A high response rate of 69% was achieved in this sample due to the careful consideration the researchers took with the design, piloting and obtaining the sample for the study.

### **Ethical Approval**

Ethical approval was obtained from the Director of Public Health Nursing, Galway.

### **Informed Consent**

The issue of informed consent is an ethical concern for all research approaches. Participants must understand the nature of the research being undertaken, have significant information to make an informed choice, have an understanding of how the data will be recorded, used and shared (West & Brothie, 2003). These issues were addressed through an introductory letter that accompanied the questionnaire. In this study, informed consent was given when the respondent completed and returned the questionnaire.

## **Data Analysis**

Quantitative data was collected and the coded. The data was inputted into the Statistical Package for Social Services Version No. 15. Descriptive and frequency statistics were then utilized.

Qualitative data was analyzed by using content analysis. Content analysis was used to analyse the collected data in the form of comments for the open-ended questions. The data was thematically analysed under appropriate key words and associations drawn between similar themes and ideas. This was performed on a small number of open-ended questions in the questionnaire.

## **Conclusion**

The data collecting instrument used was the questionnaire, which included both 'open' and 'closed' questions. Reliability and validity of the questionnaire was tested as part of the pilot study. Permission was obtained to conduct this study and confidentiality and anonymity were ensured as part of the ethical considerations. Descriptive and frequency statistics were used to analyse the data. The study findings are set out in Chapter 3.

## Chapter 3

### Public Health Nurse Findings

#### 3.1 Introduction

A total of 66 questionnaires were sent out to the Public Health Nurses in Galway Primary Continuing Community Care HSE West and 61 were returned. This represents a 93% response rate.

#### 3.2 Demographic Profile

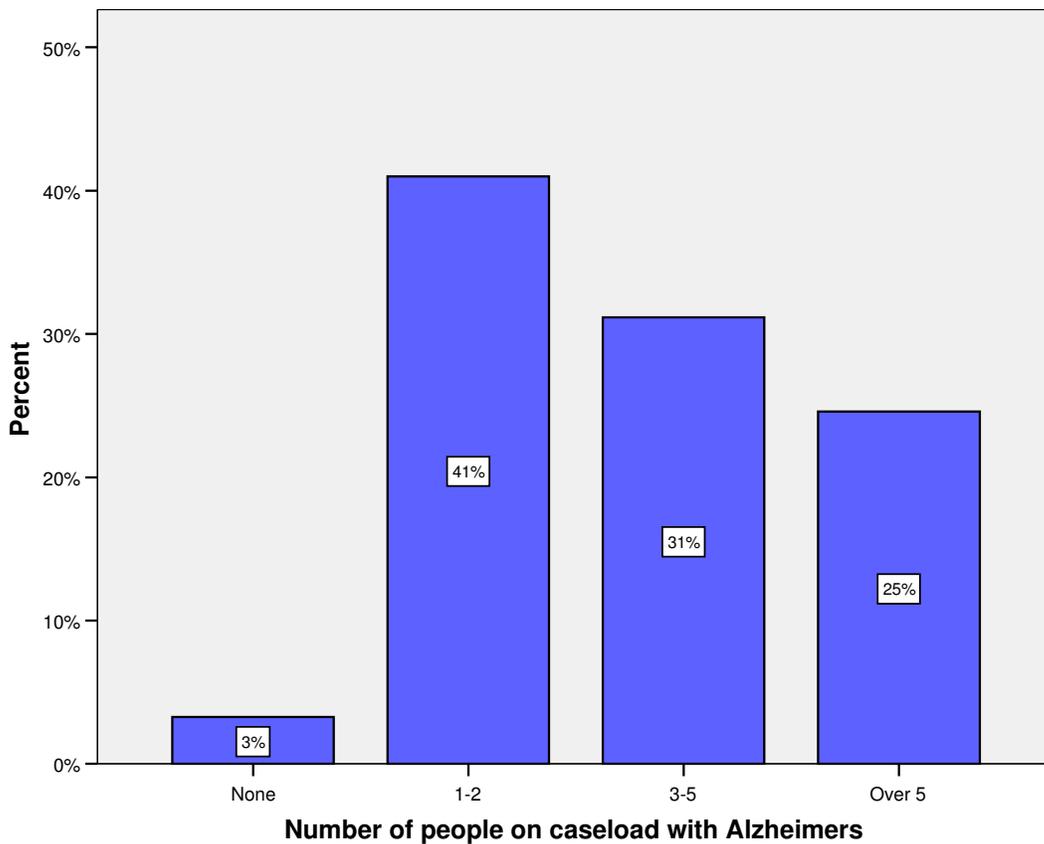
67% (n=41) of Public Health Nurses in Galway PCCC are rural based. 26% (n=16) of Public Health Nurses are urban based and 7% (n=4) are in both urban and rural areas.

#### PHN Caseload

<b>PHN Areas</b>	<b>Number of Clients w/Dementia Alzheimer's per PHN Area</b>	<b>Percentage of all PHN Clients Identified w/Dementia Alzheimer's per PHN Area</b>
Tuam	53	23%
Loughrea	37	16%
Ballinasloe	34	15%
Oughterard	30	13%
Mervue	23	10%
Shantalla	18	8%
Clifden	18	8%
Islands	16	7%
<b>Total</b>	<b>229</b>	<b>100%</b>

Table 3.1

As Table 3.1 shows, of all Public Health Nurse areas surveyed, Public Health Nurses in the Tuam area had the highest number of patients with Dementia/Alzheimer's of the total number identified at 23% (n = 53), followed by Loughrea at 16.% (n = 37) and Ballinasloe at 15% (n = 34). Significantly, these towns are located in east Galway, which means that 54% (n = 124) of the total number of patients with Dementia/Alzheimer's in Galway are in the eastern portion of the County.

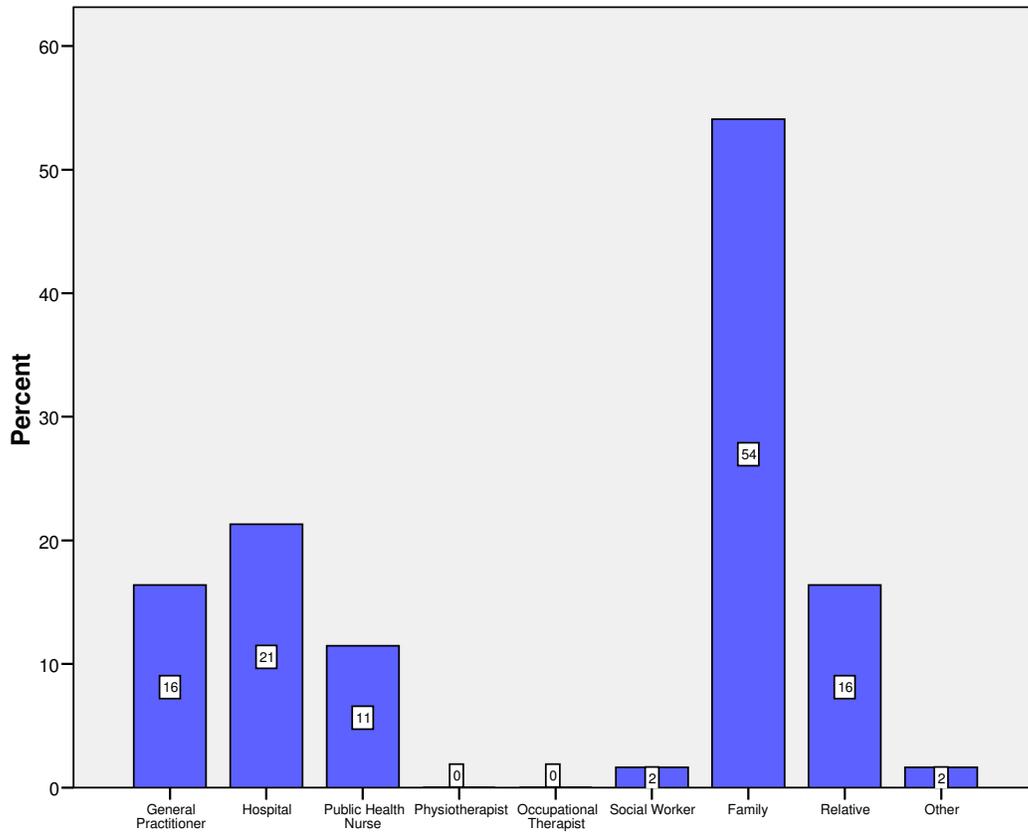


**Figure 3.1**

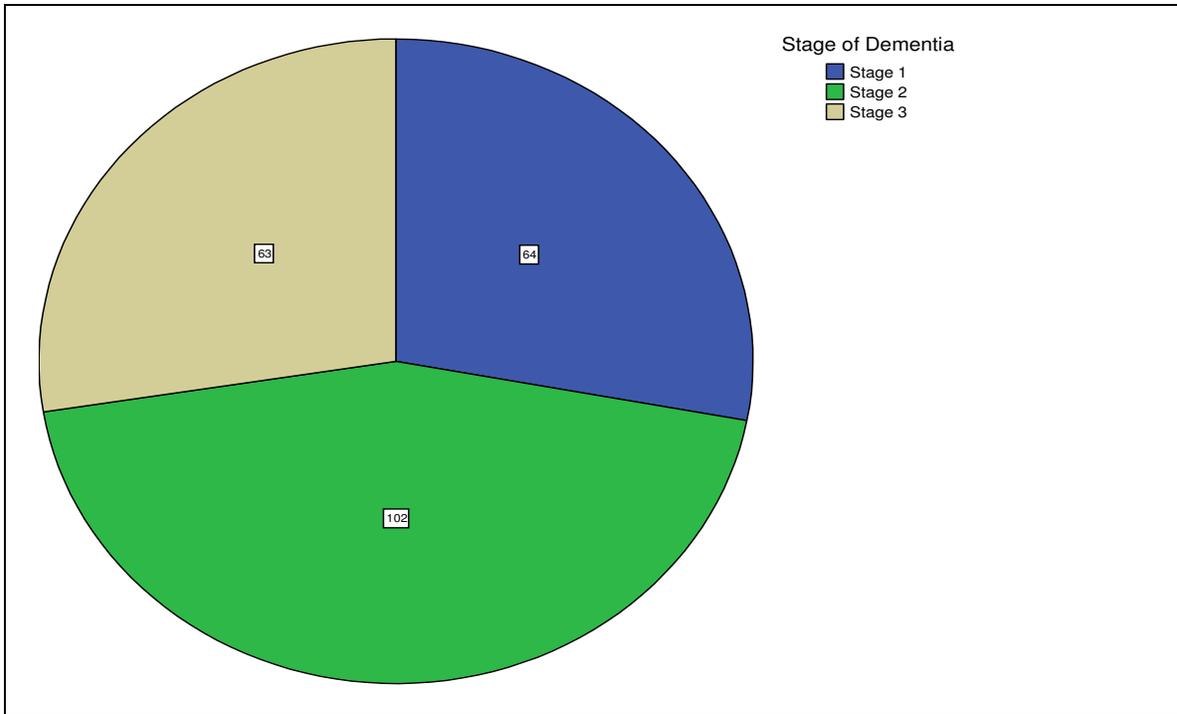
The above graph reveals that a significant 25% (n = 15) of Public Health Nurses have over 5 patients with Dementia/Alzheimer's on their caseload.

### **3.3 Source of Referral to the Public Health Nurse**

The purpose of this question is to provide an understanding and an insight into the referral pathways of the patient with Dementia/Alzheimer's to the PHN service. The vast majority 69% (n = 66) of persons with Dementia /Alzheimer's were referred to the Public Health Nurse by their family.



**Source of Referral to PHN - Figure 3.2**



**Stages of Patients with Dementia/Alzheimer's in PHN Areas – Figure 3.3**

As Figure 3.3 shows, 57% (n = 35) of Public Health Nurses had 28% (n = 64) patients in their area with Stage 1 Dementia/Alzheimer's. 64% (n = 39) Public Health Nurses had 45% (n = 102) patients in their areas with Stage 2 Dementia/Alzheimer's and 61% (n = 37) Public Health Nurses had 27% (n = 63) patients in their area with Dementia/Alzheimer's. This research reflects the need for earlier diagnosis of Dementia/Alzheimer's, which would lead to less strain on the patient, their family and the health care system.

## **Chapter 4**

### **Carers' Findings**

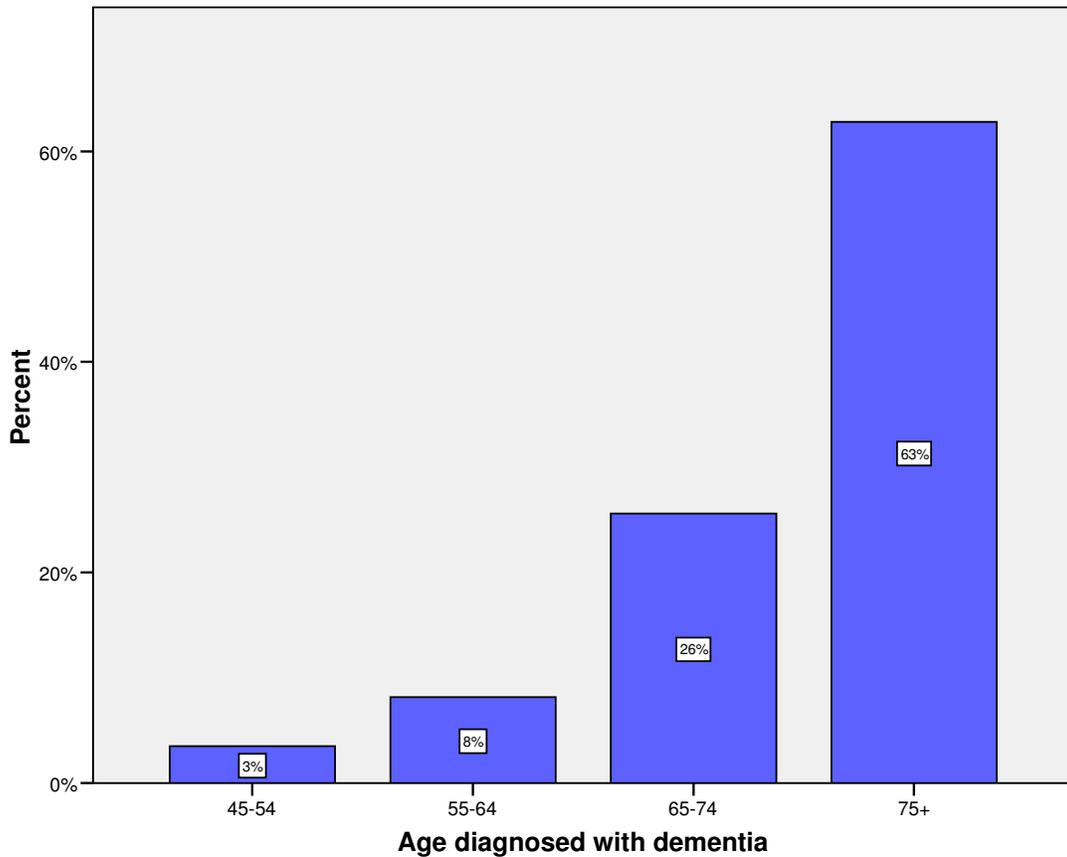
#### **4.1 Introduction**

The purpose of this questionnaire is to provide an understanding of what is involved in the day to day caring of the person with Dementia/Alzheimer's at home. This questionnaire records information about the carer themselves, the person they are caring for and the services they avail of. It is hoped that this questionnaire will provide an insight of the daily dimensions of caring for a person with Dementia/Alzheimer's.

A total of 229 patients were identified with Dementia/Alzheimer's from the Public Health Nurse Questionnaires. All patients had a carer. Of these 229 carers, 61% (n=140) of carers gave permission to be part of the study. One hundred forty questionnaires were sent to the carers who consented, of which 69% (n=96) of the questionnaires were returned. This represented a 69% response rate. Some reasons for non-participation were admission to long term care or the death of the care recipient.

#### **4.2 Profile of the Person with Dementia/Alzheimer's**

83% (n = 80) of the people in this survey had been diagnosed with Dementia/Alzheimer's. 69% (n = 66) of people in this study with Dementia/Alzheimer's are female. Socio-demographic characteristics of individuals with Dementia/Alzheimer's show that 62% (n = 60) are living in a rural area.



**Figure 4.1**

### **4.3 Age Diagnosed with Dementia**

As figure 4.1 shows 63% (n=60) of clients were diagnosed with Dementia/Alzheimer's were over 75 years of age, with 26% (n= 25) diagnosed from 65-74 years of age.

### **4.4 Carer Profile**

The study found that 82% (n = 79) of people with Dementia/Alzheimer's living in the community are cared for by family members. 66% (n = 46) of these carers are female. Of this 82% (n = 79), 36% (n = 35) are cared for by their daughter and 20% (n = 19) are cared for by their wives.

15% (n = 14) of carers were over 75 years of age, 31% (n = 30) of carers are over 65 years and 60% (n = 58) of carers are over 55 years. For the majority of carers, 90% (n = 86) English is their first language.

#### 4.5 Duration and Extent of Caring Role

The mean number of years that carers were caring for the person with Dementia/Alzheimer's was six years with the highest number of participants caring for the person with Dementia/Alzheimer's for one to three years at 23% (n=21).

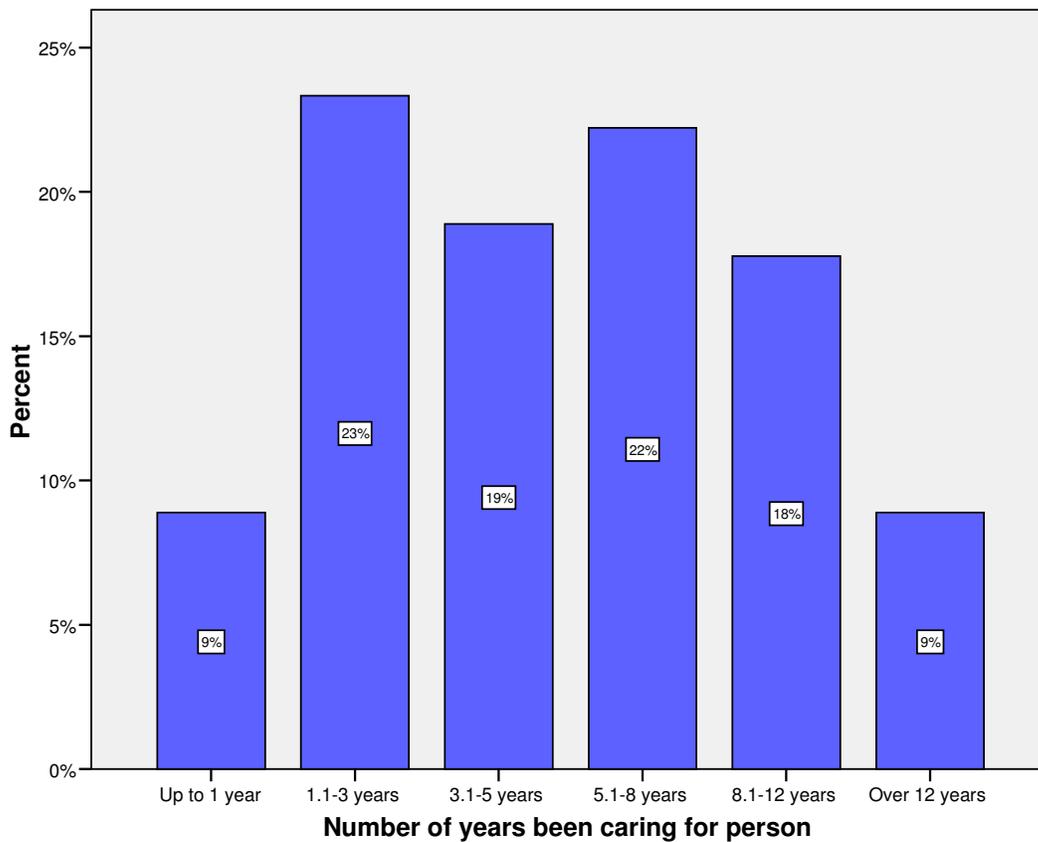
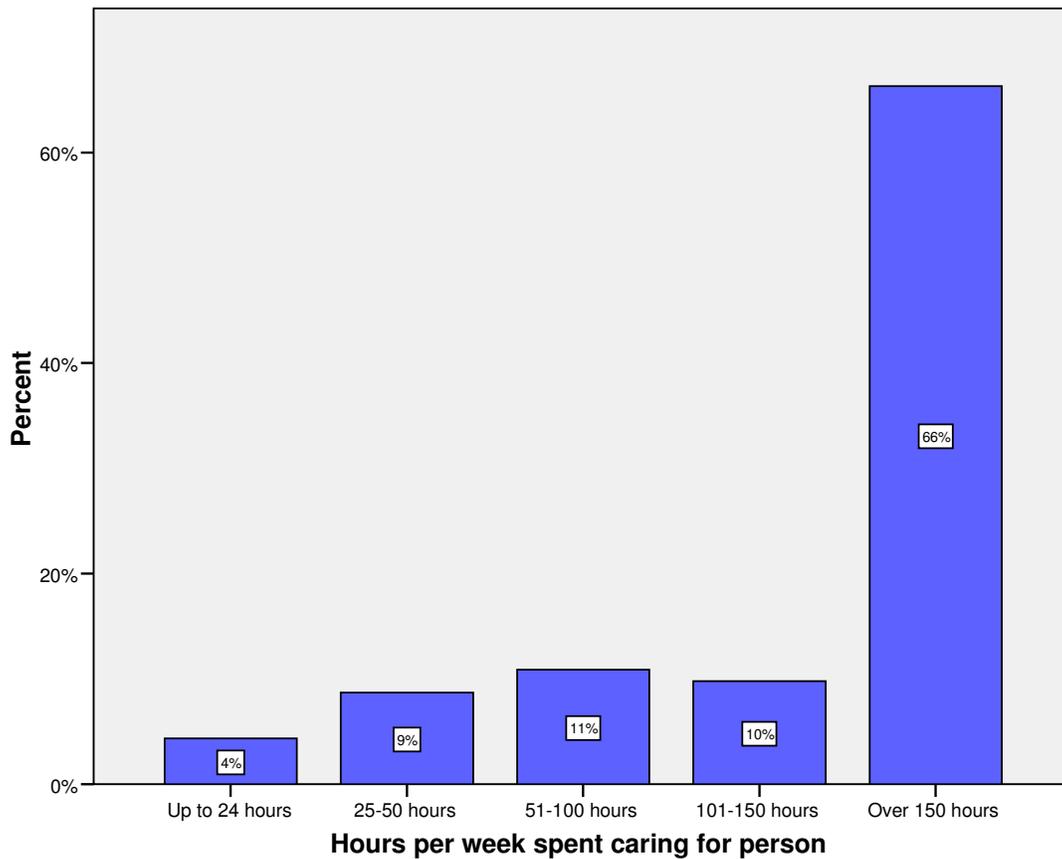
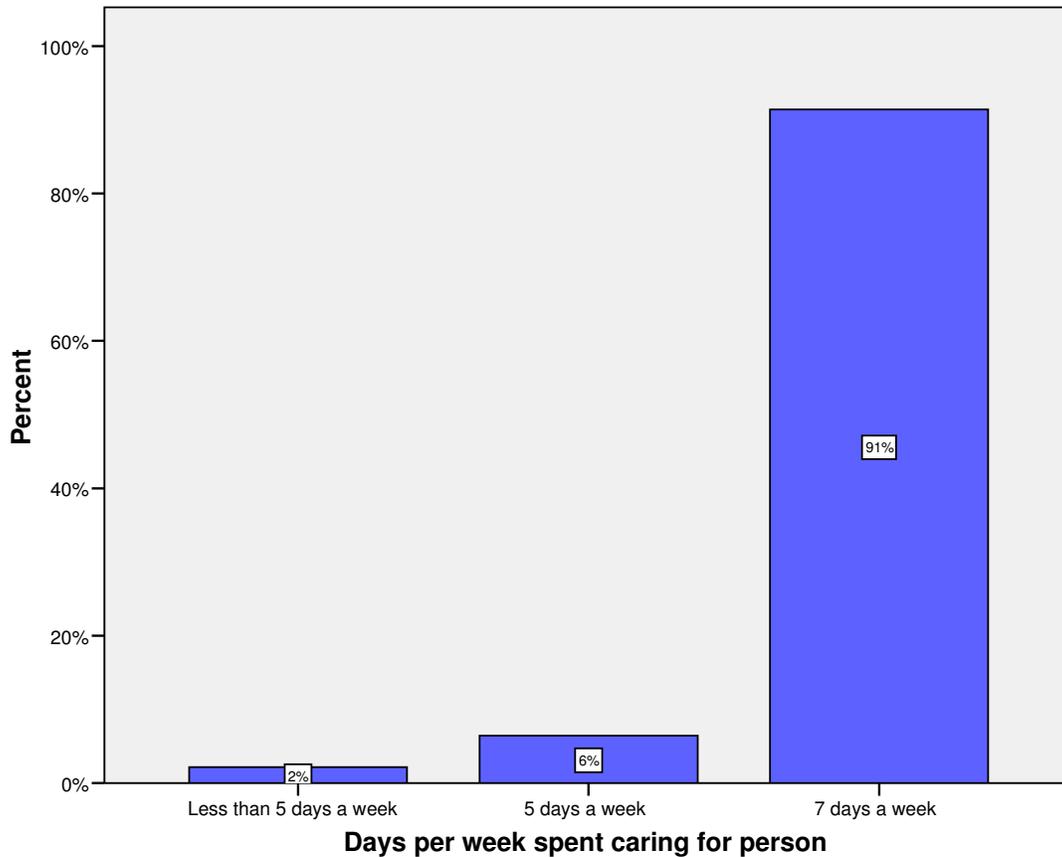


Figure 4.2



**Figure 4.3**

66% (n=63) of carers were caring for the person with Dementia/Alzheimer's over 150 hours per week, 11% (n=11) carers spent 51 to 100 hours, 10% (n=10) of carers spent 101-150 hours, 9%(n=9) spent 25-50 hours and 4% (n=4) spent up to 24 hours per week caring for the person with Dementia and Alzheimer's.



**Figure 4.4**

91% of carers (n = 88) cared for the person with Dementia/Alzheimer's seven days a week, 6% of carers (n = 6) cared for the person with Dementia/Alzheimer's five days per week. The mean number of days per week spent caring for the person with Dementia/Alzheimer's was 6.7.

#### **4.6 Greatest Source of Support**

Carers stated that the Public Health Nurse at 44% (n = 42) is their greatest source of support followed by the General Practitioner at 43% (n = 41), Alzheimer's Society/Western Alzheimer's at 21% (n = 20), Relatives at 19% (n = 18), Geriatrician 4%

(n = 4), Doctor in Hospital 3% (n = 3) and Social Worker (n = 3). Others at 10% (n = 10), included services such as home help and the Carers Association.

<b>Greatest Source of Support</b>	<b>%</b>
Public Health Nurse	44
General practitioner	43
Alzheimer's Society/Western	21
Alzheimer's	19
Relatives	10
Others	4
Geriatrician	3
Doctor in Hospital	3
Social worker	

**Table 4.1**

#### **4.7 Information Provided to Carers**

When carers were asked whether they had received any information regarding caring for the person with Dementia/Alzheimer's in the following areas only 13% (n=12) had received any information on basic nursing skills. 11% (n=11) had received information on first aid. 17% (n=16) had received information on lifting technique. 16% (n=15) had received information on hygiene. 4% (n=4) had received information on counselling. 12% (n=12) had received information on occupational therapy 2% (n=2) of carers had received information on relaxation therapy 3% (n=3) of carers had received information on reminiscence therapy.

<b>Information for Carers</b>	<b>No.</b>	<b>%</b>
Basic Nursing skills	12	13.%
First Aid	10	11.%

Hygiene	14	16%
Lifting technique	15	17%
Counselling	4	4%
Relaxation technique	2	2%
Reminiscence therapy	3	3 %
Maintaining independence	5	6%
Occupational therapy	11	12%
Other	14	16%

**Table 4.2**

Carers were asked whether they had any information, within the last year, regarding the subjects in Table 4.2. However it emerged that only 17% (n = 16) of carers had been referred for lifting techniques and 13 % (n = 12) of carers had attended for basic nursing skills. Skills such as maintaining independence were 6% (n = 6) with relaxation therapy scoring the lowest at 2% (n = 2).

#### **4.8 Services For Person With Dementia/Alzheimer's**

<b>Services Most Often Utilized</b>	<b>%</b>
Public Health Nurses	94%
General Practitioner	90%
Home Help	78%
In Home Respite	50%
Residential Respite	47%
Hospital respite	40%
Day care	43%

**Table 4.3**

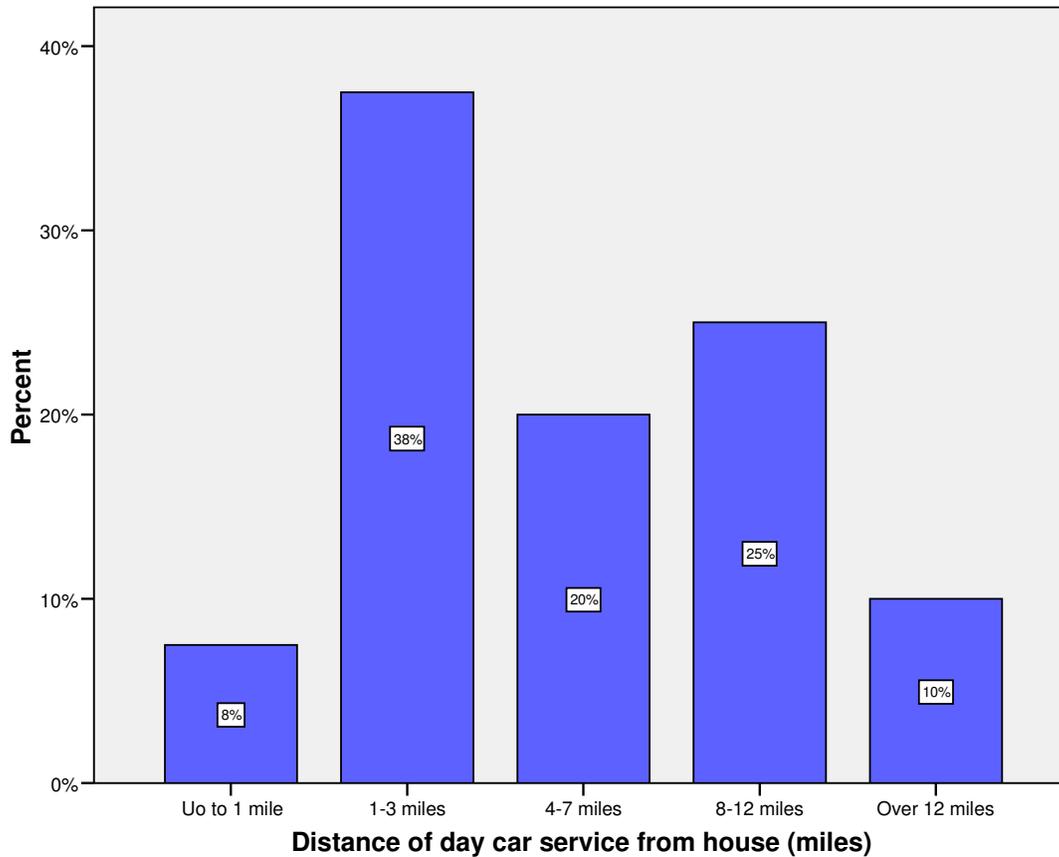
94% (n = 90) of carers found their Public Health Nurse was the service that they relied on most, closely followed by the General Practitioner 90% (n = 86) and Home Help service at 78% (n = 75).

#### **4.9 Day Care Services**

Carers were asked about the day care services in their area. 43% (n = 41) had a day care service, 29% (n = 28) had no day care service and 26% (n = 25) didn't know about day care in their area.

#### **4.10 Distance of Day Care from Home**

The mean distance that a client had to travel to day care was 6.25 miles.



**Figure 4.5**

38% (n=37) of clients lived 1-3 miles from their day care, 25% (n=24) lived 8-12 miles from their day care centre, 20% (n=19) lived 4-7 miles from day care centre, 10% (n=10) lived over 12 miles from the day care and 8% (n=8) lived up to 1 mile from their day care centre.

#### **4.11 Access to Services**

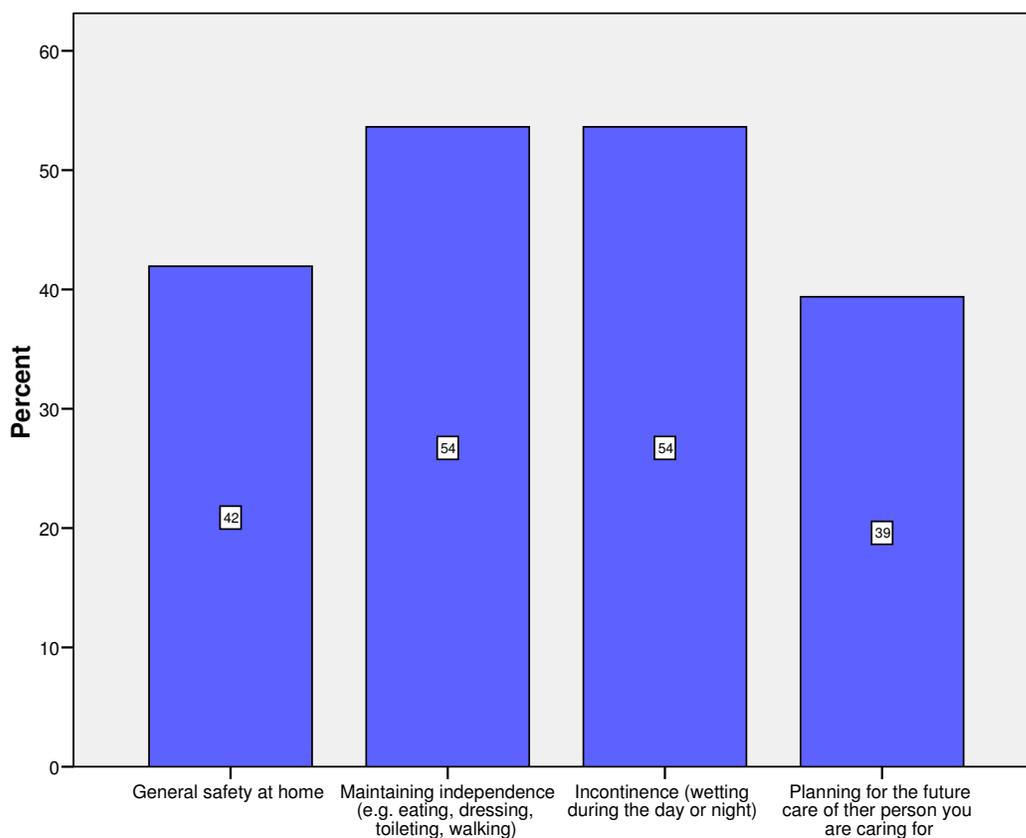
Carers were asked to indicate if there were any services they did not have access to. 17% (n=16) of carers stated that they had no access to certain services, 40% (n=38) carers stated that they had access to services and 42% (n= 40) stated that they didn't know about any services.

#### 4.12 Services Needed

30% (n = 28) of carers stated that they had received all the services that they needed for the person they were caring for. 34% (n = 33) of carers stated that they did not receive all the services that they needed and 34 % (n = 33) of carers stated that they didn't know. Of the 34%, (n = 33) of carers who stated they did not receive all the services they required, 41% (n = 18) required more home help, 37% (n = 16) requested coordination of services and 16% (n = 7) requested a specialist Public Health Nurse.

<b>Services Needed</b>	<b>%</b>
Home Help	41%
Coordination of Services	37%
Public Health Nurse	16%
Other	6%

**Table 4.4**



**Figure 4.6 – Have You Talked to any Health Professional in the past year regarding the Above Issues.**

#### **4.13 Discussion with Health Care Professionals**

42% (n = 40) of carers had discussed general safety at home with a health professional, 54% (n = 52) discussed maintaining independence of the person they were caring for, 54% (n = 52) discussed incontinence with a health professional, 39% (n = 37) discussed the planning for future care of the person with Dementia/Alzheimer's with a health professional.

## **Chapter 5**

### **Discussion**

#### **Introduction**

Dementia is one of the most common and serious disorders of later life and is a result of the progressive and rapid death of brain cells within the cerebral cortex which affects the persons level of physical, social and psychological functioning (Rabkin, 2004). Early complaints include changes in levels of functioning, forgetting names and conversations, inability to manage finances, and a difficulty in learning new skills (Rabkin, 2004).

Alzheimer's disease is the most common cause of dementia (Ruddle & O'Connor, 1993). Alzheimer's disease is a degenerative disease of the brain with prominent cognitive and behavioural impairment. The challenges of caring for a person with Alzheimer's/Dementia have become more apparent in recent years (Schneider, et al., 1999). Patients and their families are often the first to record the signs of dementia and according to Rabkin (2004) questionnaires from carers may be as accurate in diagnosing Dementia/Alzheimer's as brief cognitive tests.

This study was initiated by Public Health Nurses to develop a philosophical framework in order to provide a reference point for the planning of services for people with Dementia/Alzheimer's and for their carers. The role of the Public Health Nurse in this study was to facilitate the identification of the cohort for phase 2 of the study i.e. the clients with Dementia/Alzheimer's and their informal carers and to identify the stage of

the condition. As discussed in the methodology chapter, two separate questionnaires were used. The first, a Public Health Nurse questionnaire (n = 66) with a response rate of 95% (Appendix 2), identified persons in County Galway with Dementia/Alzheimer's and the stage of Dementia/Alzheimer's that the person was experiencing. The second carers questionnaire (n = 96) with a 69% response rate (Appendix 3) asked carers about the service needs of the clients, identified gaps in the services provided to meet the needs of persons with Dementia/Alzheimer's and services currently being provided to meet these needs.

### **Services and the Person with Dementia/Alzheimer's**

This Public Health Nurse study has identified that the person suffering from dementia was more likely to live in a rural area (61%) than an urban area (39%) and that (54%) of people with Dementia /Alzheimer's surveyed, live in East Galway. This suggests that these areas should be examined from a Public Health Nurse's perspective with regard to the provision of extra resources and services for these people. The highest percentage of people in the sample and living in the Community are at stage two at 45% (Appendix 1), compared to 28% of people at stage three and 27% of people at stage one (Appendix 1), suggesting that persons with Dementia/Alzheimer's are not being diagnosed at stage one perhaps due to reluctance of carers and the person with Dementia/Alzheimer's to seek help.

When carers were asked whether there was a day care service in their area 43 % stated yes 29% stated no with a worrying 24% stating that they did not know indicating a general lack of awareness of day care services available to them. When carers were asked

why they didn't avail of services it became obvious to the researchers that carers face insurmountable challenges in their daily lives. These challenges include the distance of day care from their house with 10% of patients living over 12 miles from their Day care centre, and 45% of patients living 4 to 12 miles from their Day care centre. Other reasons cited were, not being able to drive, high transport cost and the length of travelling time to and from centres, while 26% of carers had no information about day care services in their area and 29% of carers stated that they had no day care service in their areas. The lack of day care services available, and the lack of knowledge among carers of available day care services is a worrying finding, as day care is a significant support service not only for the care recipient, but can serve as a form of brief respite for the carer, thereby reducing caregiver burden and the ultimate relinquishment of the caring role, resulting in institutionalisation for the person with Dementia/Alzheimer's. Zarit, et al., (1999) who undertook a major evaluation involving day care for patients with dementia, found that adequate amounts of day care reduced stress indicators among carers compared with a control group not receiving the care. Similarly, Gort, et al. (2007) found that there was a tendency for there to be a greater caregiver burden and a higher collapse in caregiving at home when the patient with dementia did not use a day centre. The authors recommended the provision of carers support programmes, including information and training for carers (especially relating to the management of patient symptoms and behaviour), respite breaks for carers, day centres and telephone support to help with specific problems (Gort, et al. 2007).

This study has revealed that accessibility to day care services is not being provided adequately for the person with Alzheimer's/Dementia. According to O'Shea & O'Reilly

1999, services for people with Dementia in Ireland are underdeveloped and fragmented and access to services in the community are limited and vary from county to county. This picture portrayed by O'Shea & O'Reilly 1999 is echoed in this study with carers expressing distress and concern regarding the lack of services and isolation experienced both in regard to the carer and the person with Dementia/Alzheimer's.

### **Referral Pathways**

In this study carers were asked about the referral pathways for the person with Dementia/Alzheimer's to provide an understanding and an insight into the referral pathways of the patient with Dementia/Alzheimer's. The study found the main referral pathway to the Public Health Nurse is family/relative at 70%. It is apparent from these figures that there is no pathway specific for the patient with Dementia/Alzheimer's. 21% of patients with Dementia/Alzheimer's were referred through the hospital, 16% were referred through the GP and 2% through social work. These figures would indicate that an urgent assessment is required to provide a service for these patients with appropriate referral pathways that will result in early intervention. This is an area that a specialist Public Health Nurse would be in a position to offer invaluable expertise to enable people to be referred earlier via the appropriate pathways. This study also found that the timing of referral of the person with Dementia/Alzheimer's to the Public Health Nurses caseload is Stage 2, when the family is more likely to be in a crises situation, resulting in more resources being required by the Public Health Nurses to cope with the situation and her workload. This could be avoided by earlier diagnosis and established referral pathways which would enable the Public Health Nurse and the patient's family to plan appropriate patient centred care. Despite these difficulties it is to the Public Health

Nurses credit in County Galway that 63 patients in this study in seven areas were at stage 3 of Dementia/Alzheimer's and being cared for at home. In one particular Public Health Nurse area the maximum number of clients at stage 3 was four. This is also a credit to the carer who is providing the bulk of care in the community to highly dependent care recipients.

A review of the referral pathway system should not only be considered from a general practitioner and a Public Health Nurse perspective but also in relation to discharge planning from the hospital so that a more cohesive discharge plan is in place for the person and their carer. This study has provided Public Health Nurses with a greater understanding and knowledge of the person who has Dementia/Alzheimer's, their carer and the services that are being provided to them. It also has provided a valuable insight into the challenges faced by Public Health Nurses. Demographic changes including the growing number of older people, present a challenge to social policies in Ireland. EURODERM prevalence studies have predicted that in Ireland there are over 30,000 people with Dementia (O'Shea & O'Reilly, 1999). These research studies combined with a picture of an increasingly aged population presents a worrying snapshot of some of the challenges that are facing Public Health Nurses in the coming years.

### **Implication for Public Health Nurse Practice**

In this study, the Public Health Nurse was identified as the carer's greatest resource and support in the community at 44%, followed by the general practitioner at 43%. However it is apparent from the Public Health Nurse questionnaire that Public Health Nurses have quite a variance in demographic areas of the number of patients with

Alzheimer's/Dementia with certain areas having one to two diagnosed clients and in one area in Galway city having twelve diagnosed clients on their caseload. Due to workload demands and constraints, it is difficult, if not impossible, for the Public Health Nurse to provide the level of care that is required to maintain the person with Dementia/Alzheimer's at home. Although a large proportion of community care resources go toward the public health nursing services, the evidence suggests that the Public Health Nurse is not always in a position to give people with dementia the level of service that they require. While the public health nursing service is valued by people with dementia and their carers and reaches a substantial percentage of people suffering from dementia, visits are not frequent enough or long enough (Ruddle & O'Connor, 1993). In this study the majority of people with Dementia/Alzheimer's on the Public Health Nurse caseload in County Galway were at Stage 2 Alzheimer's (45% of sample) and that the reality for people at Stage 3 Dementia/Alzheimer is that they do not have the opportunity to live at home amongst their community.

However, from a public health nursing perspective, this higher density of patients in rural areas and in remote areas such as Connemara and the Aran Islands will require extra resources to meet the demands for caring for these patients and supporting their carers in the community. These areas need to be reviewed specifically in relation to the isolation experienced by carers and the distance day care centres and essential services such as the Public Health Nurse and general practitioners are from the person with Dementia/Alzheimer's. Irish research has revealed that the GPs have requested services such as the geriatric hit team and generally a more proactive approach in the area of Dementia/Alzheimer's (Cahill & Clark, 2002). A specialist Public Health Nurse in the

community for the person with Dementia/Alzheimer's would provide an essential link between the person with Dementia/Alzheimer's, the carer, their community and the services available. Health and well being for older people a strategy for 2001-2006 highlights the need to recognise resources that exists and the necessity of building bridges between informal and formal care. It emerged in this study that 4% of persons with Dementia/Alzheimer's attended the geriatrician and 3% attended a doctor in the hospital demonstrating a lack of communication between the carers and hospital based doctors/consultants. Again a specialist Public Health Nurse could provide that vital link between the community and hospital resulting in a holistic person centred care. It is important that this reality for carers is acknowledged as carers consistently revealed feelings of having let the person with Dementia/Alzheimer's 'down' by being unable to sustain the level of caring at home that was required. Of this sample of carers only 3% had received any form of counselling. If carers had access to counselling it could help alleviate these feelings of failure when they are not able to cope with the person with Dementia/Alzheimer's at home any more. However, as acknowledged in the literature, the aim of Community Care must extend beyond keeping older people at home and preventing placement, and should include a consideration of the sorts of enrichment that can be provided in order to promote meaningful involvement and engagement within the community. The scarcity of research studies focusing on the experience of elderly people receiving care (Seale, 1996) reinforces the need for further work in this area. Nationwide the primary objective of care programmes for older people is to maintain the individual in their chosen environment, most usually their own home. There is little doubt that for most elderly people that this is their preferred option. However, questions must be asked about the quality of life of a person suffering with Dementia/Alzheimer's living in the

Community and the services necessary to promote this, together with the quality of life of their carers and the extent of support services available to carers to support and sustain them in their invaluable caring role (Lawlor, et al 1995).

### **Carer Burden**

Dementia does not only affect the patients who suffer from it. It also imposes a significant burden on carers, causing stress, chronic fatigue, depression and irritability. Carers are not a homogenous group (O'Shea, 1999). 35% of carers in this study are male, a significant proportion with potentially different needs and expectations than females.

These differences must be reflected in the framing of Policies to support carers in the caring role (O'Shea, 1999). As this research has shown and in the literature it has emerged that caring for a person with Dementia/Alzheimer's is very stressful and carers are more likely to suffer from depression and other stress related illnesses. In this study, the mean number of years that carers were caring for the person with Dementia/Alzheimer's was six years with 9% of carers caring for over twelve years. In County Galway, 96% of carers are caring for the person with Dementia/Alzheimer's seven days a week. 66% of carers are caring over 150 hours per week, with 10% of carers caring from 100 to 150 hours per week, 11% of carers caring 51 to 100 hours per week. These statistics, which are disturbing, reveal the extent of carer burden in County Galway and also that people with Dementia/ Alzheimer's and their carers are not receiving the support that they require in the community. Carers who are managing to cope on a day to day basis are living in a demanding stressful environment which they are tolerating. A common theme that has emerged from this study is that carers do not have

the energy or time to voice frustrations at the limited services that they receive and with 66% of carers working over 150 hours to keep the person with Dementia/Alzheimer's at home in the community this is understandable. In the current study, the very high number of informal caring hours being provided per week indicates that without the input of informal care, the many government strategies and policies aimed at enabling older people to remain living in their own homes, could not be achieved. Similarly, Harrison (2007) in an evaluation of the Home Care Package Scheme in Galway PCCC found that the mean number of hours per week of informal care being provided to home care package recipients was 113.76, and over one-third of the informal carers (39%; n=15) were providing 168 hours of informal care per week i.e. 24/7 care, and, further evidenced that the mean quality of life of informal carers was very low at 35.39.

The findings in this study would indicate that service provision must be examined with regards to in home respite, home help and support for carers in general. However as the findings of this study suggests with late diagnosis due to different circumstances it is impossible for Public Health Nurses to plan and implement care pathways for the person with Alzheimer's/Dementia and their carer. In some Public Health Nurse areas service provision is being achieved in a small number of situations but it is unreasonable to expect a Public Health Nurse who has a large high dependency area to provide this level of care.

Essentially, irrespective of the intervention utilised, working together and involving the patient, carer, professional and voluntary organisations is indeed the way forward in caring for people with dementia and supporting their informal carers (Adams, 1997).

Ultimately, such support services for carers will facilitate in providing more appropriate support to carers, and will avoid the need for unnecessary patient hospitalisation and thereby postpone for as long as possible the definitive institutionalisation of the patient. Although 'The Years Ahead Report' (NCAOP, 1988) made a number of recommendations in relation to the provision of services for informal carers, evidence shows that community support services for people with dementia and their carers in Ireland are still underdeveloped and fragmented (O'Shea and O'Reilly, 1999).

### **Education**

Education is a priority in the hospital and the community to increase awareness regarding the person with Dementia/Alzheimer's. This study revealed that carers have been given very limited information with 62% of carers having no basic nursing skills, first aid or manual handling.

These results are even more significant in light of recent preliminary results from a Carers Health Survey in Ireland undertaken by the Carers Association in conjunction with the Irish College of Psychiatrists in November 2008, which found that 11% of carers were diagnosed with a medical illness, of which 41% stated that caring made the condition worse; with the most common medical illnesses being back injury reported by 27% of carers, of which 55% stated that caring made the condition worse, and high blood pressure reported by 22% of carers, of which 46% stated that caring made the condition worse (O'Brien, 2008).

The lack of information provided to carers in the current study, has been similarly evidenced in other research. In the UK, the survey of carers experiences of the NHS by the Carers National Association (Henwood, 1998) found that only 11% of carers reported that they had been given any information, which would enable them to care more safely. The Princess Royal Trust for Carers Study (Warner, 1998) also found that carers are not given the right help and information to carry out the medical procedures, which they routinely undertake. A study of carers views on hospital discharge arrangements showed carers were concerned about the limited and partial information provided (Arskey, 1997). In Ireland, O' Neill and Evans (1999) in a study in the west of Ireland identified that training, advice and support to care were major needs of carers. Sheridan et al (2003) conducted a study in the former North Eastern Health Board and found that less than 10% of carers who were caring for people with dementia, reported receiving training to assist them in their caring role. Where training was required, carers requested that it focus on the actual condition of dementia, basic handling, lifting and caring skills, as well as training the carer how to deal with behavioural difficulties and stress (Sheridan et al, 2003).

In the current study only 4% of carers had been offered counselling. This is a worrying finding as research has shown that counselling is extremely beneficial in reducing caregiver stress and collapse in caregiving at home. Providing information and counselling can reduce stress in carers. Mittelman, et al., (1996) conducted a longitudinal study in New York with spousal caregivers who were provided with sessions of individual and family counselling that were task-oriented. These sessions promoted communication among family members, taught techniques for problem solving and

patient behaviour management. It was found that patients who participated in the treatment remained cared for at home for significantly longer than those in the control group.

When carers were asked about the future planning of the person with Dementia/Alzheimer's only 39% of carers had discussed it with a Health Professional therefore indicating that for the majority of carers planning of services for the future is a difficult decision and therefore perhaps not addressed. This is an area where education and support for carers is vital to ensure appropriate planning of services for the person with Dementia/Alzheimer's.

Reminiscence therapy, which is such a vital link to the person with Alzheimer's/Dementia, was practised with 3% of people with Alzheimer's/Dementia. These results indicate that in reality education of carers is restricted to a very small number of people therefore highlighting the urgent need for an education policy to be examined in relation to carers of people with Alzheimer's/Dementia. Carers also need to be seen as individuals to be listened to by the health professionals. Carers need to be given information and training and to be in a position to share information with health professionals and each other.

## **Chapter 6**

### **Conclusions**

As Public Health Nurses, we need to articulate to the client what it is we do and the benefit of our intervention. The Public Health Nurse needs documentation that offers Identification, Assessment, Planning, Intervention and Delivery of a Comprehensive, Coordinated and Integrated Nursing Service to their clients and carers. This study revealed that early diagnosis is a key issue which should be addressed at local levels. Practice guidelines suggest that people with dementia have a right to know their diagnoses. In an Irish GP study more than two thirds of the GPs considered the MMSE to be the most reliable cognitive assessment tool (Cahill & Clarke 2002).

In this study it was apparent that the Public Health Nurse was the greatest resource for the carers in caring for the person with Dementia/Alzheimer's. The funding and allocation of a specialist Public Health Nurse in the area of Dementia/Alzheimer's would enable specialist knowledge to be shared and provide a much needed link between hospital, primary care and carers. A specialist Public Health Nurse can deal with the specific needs of people with dementia and their carers, providing an integrated approach to care, organising information sessions, dealing with dementia care needs and service care pathways, progressive and useful approaches to respite care and act as liaison with specialist mental health teams and geriatric hit teams.

The concept of Home, of links with living within one's community where people speak with specific languages and behave in traditional ways is very pertinent to this study. Individual perceptions of home will link with a person's experience of his community and perhaps improve the quality of life for Dementia/Alzheimer's patients and their carers.

## **Recommendations**

### **Recommendations for Public Health Nurses**

1. Appointment of a Specialist Public Health Nurse for Dementia/Alzheimer's in Galway PCCC should be instigated;
2. A Research Tool such as the MMSE to aid in early diagnoses of Dementia/Alzheimer's should be implemented;
3. On-going education of Public Health Nurses regarding Dementia/Alzheimer's based on research that recognises the cultural and spiritual needs of the person with Dementia;
4. Further development and validation of tools by which pain and other symptoms can be better recognised in non-communicative patients;

### **Recommendations for Carers**

#### **1. Services**

- Provide an adequate range of services and appropriate supports for carers to reduce caregiver burden and in turn to reduce the collapse in caregiving at home.
- Ensure all HSE- PCCC areas have a Manager/Coordinator of Carers Services to guide and oversee the development and delivery of services for carers.
- Identify how existing voluntary and statutory structures and services could be reorganised to improve outcomes for carers.

- Community Mental Health Teams should place as much emphasis on the carers needs as on the needs of patients with dementia, and should assess carers stress levels and carer burden and provide appropriate responsive interventions, such as social work services, community psychiatric nursing, domiciliary care workers, respite care, carers support group, to ameliorate carer burden and stress.
- Expand the range and availability of respite services (home-based and residential) to enable a flexible and responsive service to be provided that will help sustain the capacity to care and maintain the health and wellbeing of Carers.
- Expand the availability of day care services that will help sustain the capacity to care and maintain the health and wellbeing of care recipients and their informal carers.
- Introduce a specific Counselling Service for carers, as many carers may experience emotional and psychological difficulties associated with caring.
- Provide the necessary resources to establish an adequate level of local Carers Support Groups to promote social inclusion for carers and to alleviate isolation.

## **2. Education and Training**

- Develop a National Register of Informal Carers in Ireland.
- Ensure that all HSE areas have an information and advice service for carers.

- Ensure that Citizens Information Centres throughout the country are adequately resourced to identify and proactively disseminate information on the rights and entitlements of carers and to assist them in accessing appropriate services.
- Develop a dedicated information website for Family Carers.
- Establish a publicity campaign to promote awareness among carers and health service personnel about the importance of Carers looking after their own health and well-being and the support services available for carers. This could be undertaken during the annual National Carers Week. This may be significant in identifying ‘hidden carers’, who may be most in need of support services.
- Ensure that all HSE areas have Carer education and training strategies in place.
- Ensure that Carers have equality of access to lifelong learning.
- Provide funding to allow all Carers access to accredited training in caring skills, which should be linked into the National Framework of Qualifications (NFQ).
- Education and training programmes should be established for carers in preparation for the care giving role.
- Provide specific Training Programmes for all Family Carers of patients with Dementia, incorporating problem solving techniques and behaviour management, such as, how to deal with negative behaviour associated with dementia; how to prompt and communicate effectively, and how best to interact with the patient.

- Voluntary organisations and other statutory organisations, should work in partnership to develop specific back to work training programmes for carers whose caring role has ceased.
- Ensure that such education and training is accessible to carers, including the use of eLearning where appropriate.
- Provide Carers with the necessary respite services to enable them to participate in training.

### **3. Needs Assessment**

- A standardised and comprehensive Carers Needs Assessment protocol should be developed and piloted to identify the range of services and levels of support to be provided. By providing carers with an assessment of needs and monitoring carers stress, then intervention can be provided to reduce physical and mental health decline.
- Initial assessments should be performed as early as possible, to prevent health or social problems arising, or to identify such problems before they progress further. Periodic re-assessments should be undertaken to monitor any progression of carergiver burden.
- Appoint key workers whose role is to carry out the Carers Needs Assessment and to manage the support packages put in place. This could be achieved through a review of existing PCCC professionals and the integration of this initiative as part of existing roles and structures.

#### **4. Research**

- Ongoing evaluation is required in order to map the quality and outcomes of support structures and services aimed at addressing carers' continuing health and social care needs.
- Further research is needed to determine whether interventions designed to increase caregiver support would decrease hospital readmissions and institutionalisation among older people.
- Research is needed to evaluate workplace initiatives to support carers.

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## Appendix 1

### Stages of Dementia and their Association with Falls

References:

#### Stage 1 Early Dementia

Diminished short-term memory. Patients repeatedly ask same question. The inability to locate belongings may lead to paranoia. Word finding is difficult. Personality changes. Emotional lability, mood swings, depression – Euphoria. May become increasingly irritable, hostile and agitated.

Merck Manual of Geriatrics

May compensate reasonably well and follow established routines at home. Any change however will lead to disorientation.

#### Stage 2 Intermediate Dementia

The patients' ability to perform basic activities of daily living becomes impaired. The patient cannot learn new information. Increasing disorientation in time and place. Patients become lost.

Significant paranoia delusions loss of self-perception.

#### Stage 3 Severe Dementia

Patients with severe dementia cannot perform activities of daily living and are completely dependent on others. Loss of reflex motor tasks put patients at risk of malnutrition and aspiration.

## Appendix 2

# QUESTIONNAIRE FOR PUBLIC HEALTH NURSES

PLEASE CIRCLE THE RELEVANT NUMBER(S) TO EACH QUESTION

### 1. Are you working in

Rural Area	1
Urban Area	2

### 2. How many people on your caseload are known to you with Dementia/Alzheimer's?

### 3. What is the most common source of referral of clients with Dementia/Alzheimer's to the Public Health Nursing Service?

General Practitioner	1
Hospital	2
Public Health Nurse	3
Physiotherapist	4
Occupational Therapist	5
Social Worker	6
Family	7
Relative	8
Other	9

### 4. At what stage of Dementia/Alzheimer's are your clients?

PLEASE REFER TO BLUE LEAFLET ENCLOSED

Stage One - Number of Clients

Stage Two - Number of Clients

Stage Three - Number of Clients



## Appendix 2

## Appendix 3

### QUESTIONNAIRE FOR CARERS

**PLEASE CIRCLE THE RELEVANT NUMBER(S) TO EACH QUESTION**

#### **Section 1 – About Yourself – The Carer**

**1. What relation are you to the person you are caring for?**

Wife	1
Husband	2
Daughter	3
Son	4
Daughter-in-law	5
Son-in-law	6
Cousin	7
Neighbour	8
Friend	9
Partner	10
Other – Please state	

**2. Are You**

Male	1
Female	2

**3. Age Group:**

Under 18	1
18-25	2
26-34	3
35-44	4
45-54	5
55-64	6
65-74	7
75+	8

**4. Are you or any of the household a member of the following:**

Native Irish	1
Travelling Community	2
Eastern European	3
Asian	4
Refugee	5
Asylum Seeker	6
Migrant Worker	7
Leave to Remain	8
Other – Please state	

### Appendix 3

5. What language do you normally speak at home?

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**Section 2**     **This is about the person you are caring for:**

6. Is the person you are caring for living in an urban or rural area? Please circle

Urban	1
Rural	2

7. What gender is the person you are caring for? Please circle

Male	1
Female	2

8. How long have you been caring for the person \_\_\_\_\_

9. Has the person you have been caring for been diagnosed with dementia?

Yes	1
No	2
Don't know	3

**And if so at what age were they diagnosed with Dementia.  
Please circle the relevant box below:**

Under 18	1
18-25	2
26-34	3
35-44	4
45-54	5
55-64	6
65-74	7
75+	8

### Appendix 3

**10. In the last year have you received any information on the following?**

**Please circle the relevant boxes**

	<b>yes</b>	<b>no</b>
Basic Nursing Skills	1	2
First Aid	1	2
Hygiene	1	2
Lifting Technique	1	2
Aromatherapy	1	2
Reflexology	1	2
Counselling	1	2
Relaxation Technique	1	2
Reminiscence Therapy	1	2
Maintaining Independants	1	2
Occupational Therapy	1	2
Other – Please state		

**11. Who has been your greatest source about caring for people with someone with Alzheimer’s.**

**Please circle the relevant box.**

GP	1
Geriatrician	2
Public Health Nurse	3
Relative	4
Doctor in Hospital	5
Social Worker	6
Alzheimer’s Society	7
Other – Please state	

**12. How many hours per day do you spend caring *for the person you look after?***

\_\_\_\_\_

**How many hours per week do you spend caring for the person you look after?**

\_\_\_\_\_

**How many days per week do you spend caring for the person you look after?**

\_\_\_\_\_

### Appendix 3

#### Section 3 Services

13. What services have been used by the person you are caring for in the last year? Circle as many as appropriate.

	yes	No
GP	1	2
Public Health Nurse	1	2
Home Help	1	2
In-home respite	1	2
Residential respite	1	2
Hospital Respite	1	2
Day Care	1	2
Other – Please state		

For any of the above services you did not use could you please give the reason for not using them:

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14. Is there a Day Care Service in your area?

Yes	1
No	2
Don't Know	3

15. If yes, how far approximately is it from your house?  
\_\_\_\_\_ miles

16. Are there any services that you don't have access to? Please circle

Yes	1
No	2
Don't know	3

**Please comment:** \_\_\_\_\_

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### Appendix 3

**17. Have you talked to any Health Professional in the last year about any of the following?**

**Please circle as many as possible:**

		Yes	No
A	General Safety at home	1	2
B	Maintaining Independence Example: (eating, dressing, toileting, walking)	1	2
C	Incontinence: Wetting during the day or night	1	2
D	Planning for future care of the person you are caring for	1	2
E	Other Please specify:  _____  _____  _____  _____		

**18. Did you get all of the services you thought you needed for the person you are caring for**

**Please circle:**

<b>Yes</b>	<b>1</b>
<b>No</b>	<b>2</b>
<b>Don't know</b>	<b>3</b>

**If no please specify** \_\_\_\_\_

\_\_\_\_\_

Thank you very much for participating in this Questionnaire.

*Please return to:*  
**Marilyn Kelly/Mary Moran, Public Health Nurse,**  
**Alzheimer Study,**  
**PCCC,**  
**HSE West,**  
**25 Newcastle Road,**  
**Galway.**

*Stamped Addressed Envelope Enclosed*

## Appendix 3

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## **Appendix 4**

### **Letters from Carers**

We have been totally taken aback by change in my mother's behaviour over the past six months. After seven years of passive, quiet behaviour, we did not expect things to change so quickly and so drastically. She is now agitated, bossy, shouting and aggressive. I feel we have crossed over a border into the realms of mental illness now. I have been totally frustrated in trying to find a suitable medication to sedate her without knocking her out. This is an area where GPs are unhelpful because they do not seem to have enough information on problems associated with Alzheimer's and the drugs they are prescribing. Administering and monitoring and changing these medications have been very difficult. I spoke to a nurse working in a nursing home about this and she was able to give me names of medication which I then took back to the doctor. She is at the 'coal face' and was able to advise on what can be done. I feel there is an urgent need for one person to call on families and discuss problems like these. They would need to have a lot of training, background on care of the elderly, especially people with Dementia and Alzheimer's, what works and doesn't work in difficult situations. In the early stages of this disease, advice would have been helpful in keeping the person stimulated or exercised. This is now too late for our situation.

## Appendix 4

My mother has vascular dementia but at the moment can manage dressing, very light cooking, shopping and has good social skills. She is not inclined to mix with people outside her own family and so has to be brought everywhere and 'minded.' She is on Warfarin and goes for blood tests every two weeks. I have to juggle working hours to get her to these appointments and then back to the hospital for results. My weekends are devoted to bringing her to town and to mass on Sunday. I also cook dinner for her and my mother-in-law on the weekends. My husband and our three children all help in the care of both mothers.

My mother's main daily focus is to get me some lunch. I work five miles from home and try to get home each day. If I have to work late or adjust lunch breaks, this can be confusing for my mother as [I think] this is how she marks time.

At present, I am trying to get some lady with transport who could take my mother out and stimulate her mind. To date, I have found no one that my mother would take to.

Thank you.