

**Living with Dementia in New Zealand:
An Action Research Study**

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**A thesis submitted to Auckland University of Technology
in fulfilment of the requirements for the degree of
Doctor of Philosophy (PhD).**

April 2011

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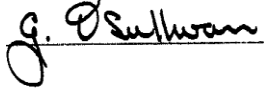
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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the qualification of any other degree or diploma of a university or other institution of higher learning, except where due acknowledgement is made in the acknowledgements.

Signed:

A handwritten signature in black ink, appearing to read "G. O. Sullivan", written over a horizontal line.

Dated: 25.11.11.

Acknowledgements

In the context of this intrepid academic journey, I am grateful for the help I have received from many people but I offer special thanks to Professor Clare Hocking for her constant support. Her confidence in my ability has never waned; she is generous with her time and always gives liberally of enthusiasm and intellect. I am also sincerely grateful to Dr Deb Spence for sharing her knowledge and experience. Together, their feedback has guided my reflections and added new dimensions to my vision. In addition, I am indebted to Filomena Davies for making time to edit this work.

I give thanks to the Northern Y Regional Ethics Committee who approved my initial application NTY/05/08/054 on 10 October, 2005. To Auckland University of Technology Ethics Committee who approved my application 05/213 on 21 November, 2005. To the Auckland District Health Board who approved my application A+3504 on 6 June, 2006. To the Northern Y Regional Ethics Committee who approved applications to include additional locality organizations on 8 June, 2006 and again on 29 March, 2007.

I am deeply indebted to the participants in this study. They invited me into their home and willingly shared their time and knowledge, trusting that the information would be used to benefit others who live with dementia. Without their involvement, cooperation, reflections, constructive criticism and feedback, this project would not have been possible.

In the context of my private life, I am grateful to my husband Frank, our daughters Shanon, and Clare, and sons Dominic, Conor, and Séan. Our way of life changed, and you each found your own direction. May you all reach the stars of your greater destiny through a rich, satisfying, and purposeful life, and always be mindful of others.

I feel sure my much loved Mum and Dad would be well satisfied, for they taught me the value of integrity and to treat others as I would like to be treated. I also want to thank my sisters and brother in Scotland, for their love, prayers (and all the candles). With regard to ongoing support and interest in this study I am grateful to friends Mandy MacLean, Jill Firmin, and (the late) Mary Sinclair.

Last but certainly not least I pay tribute to the memory of Una Platts whose vision, courage, tenacity, dignity, self respect, intelligence, and wonderful sense of humour gave me a new understanding of the intricacies of dementia. She was a unique lady, who unwittingly changed the course of my life.

Abstract

The aim of this study was to undertake a systematic inquiry into the question of how people who live with dementia in the community can be supported to engage in daily activities. It is well known that dementia affects functional abilities yet little research has been done to produce an in-depth description, from people who have dementia and their family/whānau, of the inherent difficulties encountered with functioning on a day to day basis in the community, when living with dementia. In a quest for greater understanding, action research, underpinned by critical hermeneutics, brought together action and reflection, theory and practice to generate knowledge that can be used to further inform action. Described as informed committed action, the aim of action research is to act in the world, to practice and to do rather than simply engage in discourse.

International trends call for inclusion, and research indicates that people with dementia have an important role to play in identifying their own support needs. Consequently, eleven people with mild to moderate dementia and eleven family/whānau members were recruited to engage in dialogue with the researcher, to enter into discourse with each other in focus groups, and to engage in action on their own behalf. Data were gathered by interviews and observations in participants' homes and community settings over four years. Data collection and analysis were reciprocally integrated, and the participants engaged in the production of knowledge.

The process of critical hermeneutic data analysis had three stages, each of which was informed sequentially by Lewin's (1948) cyclic process of action i.e. observe, reflect, act, evaluate, and modify. In this way actions were grounded in and evaluated throughout the research process. Coded data generated categories. The adequacy of the categories was evaluated to clarify emerging understandings. Further actions were then modified to enhance understandings.

Three interacting themes emerged from the process of analysis: The nature of being in the world with dementia, Difference, and Prejudice and power. People with dementia and their family/whānau are keen to challenge the disease process, they can and do problem solve and use their initiative. However, the findings reveal a constant tension between ways of

living with dementia, political strategies, the social environment, and opportunities for occupational engagement.

The central argument arising from the findings is the significance of attitudes, in particular the personal attitudes of people with dementia. Implications for primary health care providers and policy makers highlight the need to change the ways in which dementia is perceived as the pursuit of positive attitudes may help to change histories and enable people with dementia to live well.

Preamble

Diagnosed with dementia (probable Alzheimer's) in her early 80s, I first met Ana when she was 84 years of age. Unique in her way of life, Ana had lived on the same section of land nearly all her life. What is more, she had lived alone for over 35 years in the house she had designed for herself and her mother over 40 years previously. She had no immediate family, but friends who knew her well and supported her were of the opinion that, despite her age and failing memory, it would be best if she could stay in her own home. At the time I was working with Home Care, a support service provided to older people living in the community. I used to call on Ana, help her with her shopping and check that she had enough food for the day. In those days, a meal was delivered Monday to Friday by 'Meals on Wheels' and Ana would make that one meal stretch over lunch and dinner. She also had a caregiver who came in two mornings a week to help her shower. On other days she would get up and dress by herself before preparing her breakfast which consisted of cornflakes, a banana, and a pot of tea. Another caregiver came in on Saturdays to check on her, otherwise she fended for herself.

So began a relationship from which I would learn a great deal about the intricacies of dementia. For instance, people with dementia are often said to be confused, but exactly how does one define confused or confusion? The Collins Concise Dictionary (2001) defines them as "lacking a clear understanding of something, mistaking a person or thing for another, bewilderment, lack of clarity, and disorder" (p. 184). This definition and others like it lead us to think that people with dementia live in a permanent state of bewilderment, and their actions or responses are always muddled or mixed up somehow. In my dealings with Ana, I found misunderstandings or 'confusion' could easily be rectified if missing pieces of information were supplied. Conceivably this served to refresh information that was previously known but had been forgotten. Alternatively, it may be that presenting the facts in a simple and straightforward manner enabled Ana, who was very astute, to use her innate sense of judgment to make a rational decision about issues that arose.

As an outsider looking in, I used to think that Ana had led a fortunate life however; I doubt that she would have agreed. On leaving school, she trained as a school teacher and began

her working life during the depression. Teaching jobs in Auckland were scarce at the time and so Ana was sent off to teach in country schools. Being an avid reader, she used to say the greatest hardship she faced in the country was a scarcity of books. Eventually she secured a job in Auckland and taught at various primary schools before retiring in 1956 to pursue her interest in art.

Ana had a keen eye for shape and form, and she was fascinated by faces. Many times I heard her comment on a distinguishing feature that would have gone unnoticed by a less observant person. Art was her passion, and she spent many productive years in her later life drawing portraits in charcoal and pastel, as well as flower studies in pastel. She was highly respected by staff at the Auckland Art Gallery and moved in a social circle of well-known artists and writers of the day. She traveled the country researching the art history of New Zealand and wrote three books, two of which were published. Furthermore, studying art, and in particular portraiture, took her around the world. She had little interest in mundane things like cooking and cleaning.

In trying to work out her likes and dislikes, I asked Ana one day if she had previously done her own cooking and housework. She replied “*certainly not if I could help it.*” When asked what she used to eat she said with a smile, “*An egg thing.*” “*What’s an egg thing?*” “*An egg and anything in the cupboard.*” With her declining capacity to care for herself, these skills, or lack of them, took on a new significance which is why her friends sought help from a community support service. However, all too often other people (caregivers) assigned to help Ana wanted to clean the house, but that was not at all what she wanted. Ana’s home reflected her passion for painting, portraits and reading, and she liked it the way it was. The walls were covered with paintings, many by well-known artists, and portraits she had drawn. She had books on every available surface and she would not tolerate people trying to change her way of life.

Instead, Ana wanted to engage in dialogue, she derived great pleasure from talking to people and was always interested in hearing what was happening in other people’s life. She was an articulate and accomplished raconteuse who could talk to anyone. In particular, she liked to reminisce, and given the opportunity, to talk about art. Her knowledge and skill were clearly obvious and she could usually remember significant detail when it came to art.

Alas, the fact that she often told the same story over and over again, or asked the same questions repeatedly, was a trial to many caregivers and they would leave because they lost patience with her ‘confusion’. Consequently, Ana’s support system was inconsistent, and what was worse, sometimes those who called really upset her because they wanted to enforce their values in her home. They obviously didn’t understand Ana’s needs and underestimated her capacity to make decisions.

When I first met Ana, she could compensate for memory lapses with her agile brain and quick wit. She was very perceptive and for many years she used her diary diligently to keep track of daily activities. I gradually took more responsibility for Ana’s care because her elected power of attorney, her cousin, and few friends were all in older age themselves, and although they were adamant she was better cared for in her own home, they could not actively help her. When Home Care ceased to exist, I became her key support person. In the final stages of her life, when Alzheimer’s disease had taken its toll and Ana had difficulty recognizing friends, possibly because she didn’t see them very often, she always responded to me.

Contrary to the common belief that people with dementia reach a stage whereby they do not recognize family and friends, I believe Ana always recognized me. She may not have remembered my name, but there could be no doubt that she knew me. In the latter years of her life, she could be quite irascible and many, many times caregivers would ring saying that Ana wouldn’t do this or she wouldn’t do that. I would go along and with little effort, the task, whatever it might be, would get done. I often wondered why that was and initially decided, because I have a Scottish accent, it must have been my voice she recognized. However, if Ana asked caregivers why she had to get up or to have a shower, they would tell her “*Because Grace said.*” Apparently that was enough of an explanation to elicit Ana’s cooperation. I now know that memories are captured in different areas of the brain and in hindsight I can see it was probably more to do with the fact that I always gave Ana the respect she was entitled to as a human being, and I was always careful to protect her dignity. Ultimately we established a bond over the years that cognitive decline could not change; she trusted me instinctively.

It was through my work with Ana that I slowly came to realize how inappropriately we judge people diagnosed with dementia. For instance, if someone or something upset Ana, she was quick to react and would get highly indignant at any apparent slight. It didn't pay to underestimate Ana. She was sharp as a tack and, as previously stated, very insightful. She didn't suffer being treated like a fool and was well able to hold her own in a verbal conflict. Although she may not have been able to remember the exact details of what had infuriated her in the days following a perceived insult, she didn't forget that someone had offended her. Many, many times, her response to an issue would leave me amazed. For instance, I remember taking her to her general practitioner for her regular monthly visit. In reality she didn't need medical intervention because she had no medical issues, but I would take her to the doctor just to ensure another health professional was involved in her care. It was comforting for Ana to know that her health was being monitored by her doctor and it was reassuring for me to have his support.

On this particular occasion we spent a good 30 to 40 minutes sitting in the waiting room, and in that time I answered the same repetitive questions over and over again. *"Where are we? Whose doctor is it? What is his name? Why are we here? What is his name? Whose doctor is he?"* Eventually we were beckoned into the surgery only to find a locum replacing Ana's own doctor who was apparently on holiday. On reading her chart, I can only assume that because she had a diagnosis of Alzheimer's disease, the doctor promptly addressed his questions to me rather than to Ana. She put up with this quietly for a while; I could see her from the corner of my eye glancing from the doctor to me. Eventually she asked *"Are you the patient or am I?"*

Caring for Ana was never dull. Take for instance the time I arrived to find her house empty. Now that was very unusual. I rang around her few friends to see if anyone knew where she was, but no-one had any idea. Finally I rang North Shore Hospital, and sure enough she had been admitted that morning. Off I went to the hospital to find out what had happened and following directions from the information desk, I came out of the elevator to hear Ana's most authoritative voice loud and clear: *"What bloody idiot brought me here?"* It turned out that someone had called at the house and, convinced by Ana that she needed a doctor urgently, the caller rang for an ambulance. When I explained what had happened, Ana thought it was very funny. She couldn't understand why she had to stay in hospital when

she felt fine, and so it would seem that once there, Ana forgot all the anxiety that had originally caused her concern, and was absolutely insisting she be allowed to go home. With some persuasion, she agreed to wait until hospital staff had completed a series of tests. In the end all test results proved negative and, when hospital staff were assured Ana was well cared for, she was discharged. As it turned out, it was very reassuring for her to be reminded of that story occasionally and to hear that *“every test available at the hospital was done and the results were all negative.”*

Ana often had occasions when she said she felt unwell and I came to realize that her feelings of unease were linked to anxiety, rather than a physical condition. Sometimes she got irritated because she didn't like the idea that time was passing and she was not using it productively. Also, there were times when she felt she should be doing something, but didn't know what; she had no sense of purpose. Often she could be reassured by reminding her she was a lady of leisure now, since she had retired, and usually her anxiety would slowly diminish if she engaged in conversation. She had a wonderful sense of humour and could generally be teased into another frame of mind, whereby she would be content for another little while.

Establishing routines and maintaining her personal habits were key to the success of her care. For example, as Ana's cognitive status declined, caregivers came in more frequently, and to keep Ana informed and facilitate a sense of control, they were required to write their estimated time of arrival in her diary. In the early days, Ana always checked her diary regularly for clues as to what she had been doing and what, if anything, she should be doing next. On occasion, she would get uneasy if she didn't know where her next meal was coming from however, she was reassured by knowing that someone was coming in to organize lunch or dinner, this information gave her a sense of security. Often she would stand at the door waiting for caregivers to arrive, and many times she fooled them into thinking she remembered their name. In fact, she read their name in her diary before they arrived. When it was time for them to go, if caregivers could leave her feeling safe and secure, then she would be satisfied until the next caregiver arrived.

For many years, caregivers used to take Ana for a daily walk, weather permitting, because she enjoyed walking and it was important for her to keep active. Each week I continued to

take her shopping. She didn't really have any interest in grocery shopping per se, but she liked to push the trolley around the supermarket, and she would smile and chat to anyone who gave her the opportunity, but left me to make the decisions about what groceries were required. She used to joke about her poor memory and often said "*It's lucky you know me better than I do.*" I also used to take her out for a drive once or twice a week, and it didn't matter where we went, she enjoyed being out and about. She was very observant and often commented on the fact that "*Everybody has a house in their front garden.*" All these activities were duly written in her diary to remind her that she was still active and engaged in doing things. In between times, she would occupy herself reading the paper, pottering around the house, looking at photographs and her paintings, or dozing in her bedroom.

Often she would amble out to the kitchen and make herself a cup of coffee using hot water from the tap, and every evening she had two gins and tonic before dinner, one at 5pm and one at 5.30pm, then she would watch the news before eating her dinner. In reality, the time came when I used to water down the gin so that it was fifty per cent gin and fifty per cent water. Once or twice she commented on the taste, but she never made an issue of it. Eventually she reached a stage whereby her routines fell by the wayside, and by then she was probably 92 or maybe 93. Likewise, she eventually stopped reading the paper and that was a great loss. Nonetheless, because she had been such an avid reader, it was always a comfort to her to know the paper and a selection of books were by her side. These items became what I called props and I insisted that caregivers maintained this practice. Also, many times I saw Ana use the daily paper to check the date. In this way she was able to keep track of the passage of time and at times fool others into thinking she was oriented to time and place. For these reasons, the paper was delivered long after she stopped reading it.

Social isolation was, I suspect, one of Ana's biggest deprivations as it made a great difference to her day to have someone call in and spend time chatting with her. She thrived on company and really looked forward to visitors, but her few remaining friends eventually dwindled. Some died and others had to deal with their own health issues. In the latter years, only one friend called in faithfully every week. Others who called, albeit very, very occasionally, didn't stay long. They found it hard to visit Ana because of her tendency to repeat things over and over. She needed others to move a conversation along and often friends didn't understand this, so even although she liked her own space and the tranquility

of her home, there were times when Ana was lonely. Her cousin was good in that she would ring every evening around 5.30pm to check on Ana, but the call was always very brief. Consequently, Ana's world got smaller and smaller until caregivers became her only social contact, her connection to the outside world.

Continuous adaptation and modification of Ana's routines and habits worked well over the years and when a new challenge arose, a strategy was developed to deal with it. For example, Ana would occasionally wander out to the main road. Initially this seemed harmless enough, she enjoyed strolling to the end of the driveway where she would stand and watch the world go by before strolling back. Then we discovered she was talking to strangers and this was a concern because of her vulnerability. Given that her property was down a right of way and the section was long and narrow, I suggested we erect a simple fence, with a gate, across the middle of the section. I wanted her to be able to see out and leave enough room for her to wander around the garden as she liked to do in the summer. My idea was to put a normal sliding bolt on the inside of the gate where she could see it and a childproof lock on the outside, only instead of putting the lock at the top of the gate, it was put on the bottom so that it looked like a hinge. This proved to be a very effective solution because Ana was not caged in, the garden was spacious, and although she could slide the bolt on her side she never figured out that the hinge on the back was actually another lock. Fortunately it was enough to discourage Ana, and neighbours informed me that on the few occasions she did venture out to try the gate, she usually resorted to walking round the back of the garden.

Every now and again, Ana would do something unpredictable. Like the time she rang 111 in distress and asking for help. The first thing I knew of it was when I received a phone call from the local police station. They had found my number in Ana's diary so I went off to her house fearing the worst. I thought for sure she would have to go into care although her friends were still adamantly against it. I was wrong. When I got there she was chatting, and even flirting outrageously, with the young police officer. Her whole demeanor had apparently changed once the police arrived and she reverted to her usual gregarious, gracious self. I asked Ana why she had rung the police but she didn't remember although she quite readily accepted that she had. She immediately saw it as an error of judgment and

apologized with a beaming smile. Although she realized she may have made a mistake, her problem had been solved and so she didn't seem to care.

During their assessment of the situation, I informed the police that Ana was regularly seen by her general practitioner (GP) who was fully supportive of the care she was receiving. In addition, the person who had power of attorney for her health did not think residential care was a good option. The police advised that they would take no further action as Ana was obviously well cared for. They not only acknowledged efforts to keep her in the community, they were willing collaborators. They actually went so far as to say that if she rang 111 again, they would contact me before responding to the call. Later on when the police had gone and I repeated the story to Ana, it was plain to see that she was quietly impressed and amused by her own resourcefulness. We never did figure out what prompted her to ring 111 in the first place, and as it turned out, she didn't do it again.

Understanding Ana's way of life, rather than expecting her to fit into a category designed to meet the anticipated health needs of older people, was the real key to her care. Fortunately she had the financial means to support herself, and this gave her power of attorney the freedom to make decisions that ensured her quality of life was maintained. Ana used to say that she was always careful with her money because she knew she would have no-one to look after her when she got old. She planned ahead by being frugal and asking a long-standing friend to be power of attorney for her health. Given that both her parents had lived well into older age, she anticipated she might do the same and so she wanted someone she could trust to have her best interests at heart.

Although her physical abilities declined in the last few years of her life, Ana was relatively content. When she became intolerant of noise we tried to maintain a serene environment. As her need for assistance with activities of daily living increased, so too did the support she received from caregivers. She still loved to get out and about and would happily sit in the car and watch people go by. On numerous occasions she complained that she couldn't see, but actually she never lost her eye for detail. She could still define the colour and hue of the sky, or point out significant features on people, or landmarks. For instance, one day we were sitting in the car on Takapuna wharf enjoying an ice cream, and she remarked that Auckland city was lucky to have Rangitoto, "*It's so majestic.*" Equally, she loved to see

children at play and given the chance, she always had something complimentary to say to them.

For someone who was said to be “*delicate*” as a baby, Ana proved to be very robust. Apart from her “*flaky memory*” as she called it, she had no significant health problems in later life. I only ever knew her to have “*a touch of asthma*” and the odd cold in 13 years. Despite her diagnosis of Alzheimer’s disease, she stayed in her own home, perhaps not independently, but content to spend a portion of each day, and the nights, on her own. Although she spent most of her time in her bedroom, she knew her way around the house instinctively and even though there were times when she doubted herself, she could make her way to the “*lavatory*” on automatic pilot. Often she would wander into the living room and look at the portraits of her friends and the paintings she had collected over the years, and for a long time she could relate the story behind the acquisition of each one. It always gave her satisfaction to see the books she had written, (left out on the table purposely for that reason), and when she became unsure about having written them, she would hesitate when passing but always seemed to connect with them. Being reminded that she was an author never failed to give her pleasure.

Ana never lost her social graces and she was always grateful for help received, “*Thank-you my dear, you are so good to me.*” Her nose would crinkle up and her eyes would twinkle as she smiled her thanks. She died peacefully in her own bed, aged 97. Right to the end of her life she was reassured and comforted by the knowledge that she was in her own home. This assumption is based in the obvious pleasure she showed when occasionally she would ask, “*Where am I*” and on being reminded she was in her own room, in her own bed, with her books and portraits around her, she would say “*Oh, how marvelous.*” As a result of this experience, and through ongoing studies, I have come to wonder: How can other people with dementia be supported to achieve the same sense of life satisfaction?

Chapter One

Introduction

“Knowledge comes ...but wisdom stays”

Alfred Tennyson (1809-1892)

This quotation from Tennyson speaks to me in terms of learning about dementia. Having developed a degree of knowledge through my relationship with Ana, I want to build on that and use it to help other people who live with dementia. Therefore, the research question this study was designed to address is: How can people who live with dementia in the community be supported to engage in daily activities? Understanding the ways in which Alzheimer type syndromes impact on daily life will enhance knowledge that can be used to promote optimal and effective approaches to living with dementia.

Much has been written on the subject of dementia from a scientific, a treatment, or a caregiver's perspective, yet little has been done to explore the daily lives of people who live with some form of dementia. Leaving out the knowledge of people with dementia contributes to the sense of deprivation that is commonly associated with the word *dementia*, as it implies they have nothing to say on the subject. On the contrary, I believe people with dementia should be the first source of information. As someone committed to improving social perceptions of what it means to live with dementia, I wanted to undertake research that would involve people with dementia. Motivated by theoretical standpoints while being grounded in practice, action research offered a flexible and experiential approach to generating knowledge that can inform action. This method of theorizing practice only becomes real when theories are put into action. In other words, action research is a means of working with participants who live with dementia to pursue practical solutions that may improve their personal or social situation. This direction is in keeping with international trends and has emerged alongside research which stresses the importance of treating the person and not the disease (Kitwood, 1993a).

In conjunction with these developments, this study seeks to learn from, and with, people in the early to mid stages of dementia and their family/whānau¹. Knowing that the symptoms of dementia insidiously affect intellectual capacity, I deliberately sought to recruit participants in the early to mid stages of the disease process. Although the individual symptoms differ, people in the early stages are able to register and process information, and to share knowledge. To overcome the scepticism that exists in society about the capacity of people with dementia to participate in research, I also thought it important to include family/whānau as participants. In choosing to work with people with dementia and their family/whānau who live in the community, this study was designed to generate practical information about participation in occupations that will assist people with dementia to live life more fully.

The link between occupations, the things people do in their everyday lives, and their health is well established (Yerxa, 1993; World Health Organization, 2001). Indeed, the World Health Organization's International Classification of Functioning, Disability and Health (ICF, 2001) views health as a dynamic interaction between participation, which concerns the things people do, contextual factors, health conditions and personal functioning. Further, there is a distinct relationship between the ICF and occupational therapy in that both emphasize the influence of the environment, participation, and activities on function, health, and disability in community and population-based practices. Moreover, a press release from the Senior Citizens' Minister, Ruth Dyson (2007), claimed that New Zealanders are living longer and are healthier than previous generations. What stands out in the report is the identified relationship between good health and the use of skills, talent and experience to maintain a satisfactory life, which supports the occupational perspective underpinning this study.

This is the basis from which I argue that the things people do on a daily basis contribute to a sense of health and well-being. This belief is at the core of occupational science, a discipline which promotes health through engagement in occupations (Yerxa, 1993). Occupational science is designed to contribute new knowledge to society based on the study of people as occupational beings within their environmental context. Diverse

¹ Whānau is the Maori language word for extended family. Whānau share a common bond, other than descent, it may be geographical location or a shared purpose.

occupations are so much a part of daily life that we tend to take participation for granted. Although people engage in occupations for individual reasons, occupations give a purpose to the day and make life worth living. This notion of participation in occupations is no less relevant to people with dementia (Wood, 2005; Woods, 1999a). In fact, loss of occupations is one of the most debilitating outcomes of dementia and one which has profound consequences for the person (Perrin, 1997a). International evidence has shown that things can be different (Alzheimer Scotland, 1998; Dooley & Hinojosa, 2004; Graff, Adang, Vernooij-Dassen, et al., 2008). Indeed, as a result of improved knowledge, support systems for people with dementia are changing care delivery.

Many health professionals advocate for continued engagement in normal daily activities to facilitate a satisfactory lifestyle (Nygård & Öhman, 2002; Sarvimäki, 1999). This is the specialist domain of occupational therapists who promote health and well-being through participation in purposeful occupations (Clark, Jackson, & Carlson, 2004). Studies done by occupational therapists, nurses and social workers indicate that although a number of cognitive enhancing drugs have become available for the management of dementia, it is adaptation of the physical and social environment, practical support, and knowledgeable care-giving that enable people with dementia to live a relatively normal life (Hasselkus, 1997; Lucero, 2000; McGonigal-Kenney & Schutte, 2006). Generating understandings of the support people with dementia need in the New Zealand context is the goal of this study.

Defining dementia

Dementia is a broad term used to describe the symptoms of a large group of diseases which cause a progressive decline in a person's ability to function. Defined as confusion of the mind (Anderson, 1994), dementia is wrongly thought to be a normal part of ageing. By itself dementia is not the illness, although it is a major health and disability concern globally. Usually characterised by a slow and insidious onset, most people develop symptoms over a period of years, thus generating a history of declining abilities in social and occupational functioning. Progression of the diseases which cause dementia is largely unpredictable for each individual. How and what symptoms develop will depend on the area of the brain affected, by which illness, and the unique personality traits of the person. There is no disturbance to consciousness. However, with the advent of neuro-imaging, there is little doubt when organic brain deterioration has set in. The size and shape of the

brain changes as nerve cells die, causing gaping spaces to appear between the intricate, tightly-packed channels of the cerebral cortex (Snowdon, 2001).

Dementia is usually determined clinically and psychologically by deficits in at least two areas of cognition. Among the early symptoms of dementia, memory loss is predominant. The DSM IV (American Psychiatric Association, 2000) criterion for diagnosis of dementia includes evidence of memory impairment with at least one of the following:

1. Aphasia (language disorder).
2. Apraxia (impaired ability to carry out motor activities despite intact motor function).
3. Agnosia (failure to recognize or identify objects despite intact sensory function).
4. Disturbance of higher executive functioning (planning, organising, sequencing, abstracting) (Harvey, 2003).

Difficulties should be severe enough to interfere with occupational or social activities and represent a decline from the person's previous level of functioning (Harvey, 2003). The person with dementia often seeks help from a general practitioner only after family members notice deterioration in self care (Warrington, 1996). Usually the person exhibits a general lack of interest in daily activities and symptoms may include visual and auditory hallucinations, delusions and paranoia. Known to be 'organic' illnesses, the dementias are caused by physical changes in the brain. This differs from 'functional' illnesses which are commonly considered mental illness and are associated with a chemical imbalance in the brain.

Improved knowledge has facilitated greater understanding of brain function and dysfunction, and has made diagnosis of dementia easier. Of the more than 70 known causes of dementia (Alzheimer's Australia, 2005), many are the result of other conditions. For instance, an infection or an adverse reaction to drugs, a metabolic disorder such as thyroid disease, tumours, head injuries and anaemia can all cause a form of dementia which manifests itself in poor attention, concentration, judgment, or memory. With appropriate diagnosis, dementia arising from these conditions can often be resolved. This type of dementia is not the focus of this study.

Types of dementia

Of all the organic dementias, Alzheimer's disease is the most commonly known and is said to account for 50% to 70% of all cases (Alzheimer's Australia, 2005). Alzheimer's was first identified in 1906, when Dr Alzheimer of Frankfurt, Germany, became intrigued by the experience of a middle aged woman, who was exhibiting symptoms of senile dementia. An autopsy conducted by Dr Alzheimer after the woman died revealed the now tell-tale plaques and tangled neurons that have become a hallmark of the disease. At the time, senile dementia was a well-known condition of old age but in this instance, the patient was only 51 when she was admitted to a psychiatric hospital, and considered too young to have age-related senility (Shenk, 2001). Today, many psychological symptoms in older people are classed as dementia, usually under the umbrella term, Alzheimer's disease.

Vascular or multi-infarct dementia is the next most common type and is potentially preventable. It is the only disease process causing dementia which does not have a slow and insidious onset (Nor, McIntosh & Jackson, 2005; Snowden, 2001). Other conditions include dementia with Lewy Bodies Disease, Creutzfeldt Jacob Disease, Fronto-temporal or Pick's Disease, Huntington's Disease, Korsakoff's Disease, Parkinson's Disease, and Auto Immune Disease Syndrome (AIDS). Boxing has its own type of dementia known as pugilistica (Snowdon, 2001). All the chronic dementias are a neurological condition caused by the death of nerve cells in the brain. When nerve cells die, the brain mass gets smaller (Faull, 2007).

Diagnosis of dementia

There is no known trigger for dementia. What is known is that the process begins long before the person begins to exhibit symptoms (Shenk, 2001). Although Alzheimer's and similar syndromes are serious and progressive conditions for which treatment is dubious, diagnosis is not the end of the person's capacity to make a meaningful contribution to society (Bryden, 2005; Friedell, 2000; Peskind, Li, Shofer, et al., 2006). Careful assessment by a suitably qualified health professional is the first step. Ideally this should be followed by education and specialized care as soon as possible after diagnosis to encourage people to retain and maintain existing abilities (Bryden, 2002; Sabat, 2001). On learning the diagnosis, the person and their family/whānau may well feel a sense of despair as the word *dementia* is an epithet which is commonly thought to mean 'going out of one's mind'

(DeBaggio, 2002; Friedell, 2003b; Taylor, 2007). In reality, there are as many different manifestations of dementia as there are people with it, but the idea of losing control of the self prevails.

Young onset dementia

Usually considered an illness of older age, the experience of young onset dementia is rarely considered. The incidence is rare but has been established in people as young as 35 or 40 years. Although there is no epidemiological data related to the incidence of young onset dementia in New Zealand, there is an increased awareness of the occurrence of dementia in younger people. Unfortunately these people frequently fall through a gap in the health care services. As far back as 1992, Duff (cited in Tindall, & Manthorpe, 1997) noted that family/whānau of younger people with dementia had expressed concern and annoyance that services and information providers assume that all spouse carers are older. This is not the case and the reality is that the needs of people coping with young onset dementia, whether the person or their carer, differ from those experienced by older people. As an example, occupations usually reveal the first significant signs of dementia; consequently a younger person's ability to continue working is affected. Older people have often retired and can cope without work-related income but loss of employment has a major impact on younger people who may still have dependent children, a mortgage, and other responsibilities.

Research into dementia

Researchers have identified a number of factors which contribute to brain deterioration. For instance they now know that the neurofibrillary tangles (twisted strands of tau proteins) inside the cells, and neuritic or amyloid plaques (protein clumps) that accumulate outside the nerve cells, cause changes in blood flow which affect glucose utilization in the brain (Shenk, 2001). Glucose is a source of energy for nerve cells. The energy deficit is compounded by a lack of the chemical dopamine which also reduces the brain's capacity to transport information from one nerve cell to the next. As the connections between the nerve cells deteriorate, the brain's functional capacity is affected (Shenk, 2001). Understanding this chain of events has brought about an increase in the number of studies looking for pharmacological interventions that will improve cognitive and functional outcomes.

Over the last few years there has been a vast outpouring of research about Alzheimer's disease and similar dementias and we are told that investigations into neurodegenerative

diseases are promising (Faull, 2007). Most of the research being done focuses on finding the causes, a cure, or new medications to ‘treat’ and ‘control’ the debilitating effects of the symptoms (O’Malley & Croucher, 2005). Current treatments work by regulating the action of chemical neurotransmitters in the brain, but there is controversy over symptomatic benefits (Ritchie & Lovestone, 2002). Changes in cognitive ability are said to be so small that there is no way of knowing if there is any real change so, while drugs may help to relieve anxiety and distress, claims that they can slow progression of the disease have yet to be proven scientifically (Harris, 2006; Salmon, 2006; Saul, 2007).

Comparatively little research has been done using therapeutic or non-pharmacological interventions to address the everyday difficulties experienced by people who live with dementia and their families/whānau. This is despite evidence from various academic disciplines demonstrating that the life satisfaction of people with dementia can be improved when social, emotional and occupational needs are treated alongside medical concerns (Brooker, 2001; Cahill, Drury, Lawlor, O’Connor, & O’Connell, 2003; Chenoweth, & Kilstof, 1998; Graff, Vernooij-Dassen, Thijssen, 2006; Hasselkus, 1997; Martin, & Younger, 2001; Woods, 1999b). It would seem the relationship between occupation, participation, people with dementia and their carers is relatively unexplored.

An occupational perspective

For most people, daily life is embedded in a round of routine occupations through which they maintain a healthy lifestyle and enjoy social inclusion (Townsend & Wilcock, 2004). Occupations are thus the practical means by which people remain connected to their community. However, living with a chronic condition such as dementia challenges all aspects of occupational engagement because the progressive decline in functional ability limits cognitive, social, and occupational performance.

Thus, addressing these outcomes of the disease rather than the disease itself may help to delay an increase in dependency. The search for therapeutic approaches which target factors such as participation in occupations, and outcomes such as social inclusion, has been explored by researchers’ overseas (Nygård & Borell, 1998; Wood, 2005). What is more, it has been suggested that people find meaning in daily life through engagement in occupations which promote and maintain physical and social health (Yerxa, 2002).

Therefore it follows that engagement in daily occupations needs to be understood as a source of health and well-being. Using occupation to enable people to live with chronic health conditions such as dementia is a strategy well known to occupational therapists. Supported by occupational science, occupational therapy is in a prime position to assist people with dementia. Based on the assumption that people's experience of participation in occupation influences both their health and life satisfaction, occupational science offers an integrated approach to support the profession of occupational therapy. Knowledge generated by disciplines such as social psychology, anthropology and evolutionary biology contributes to occupational science, highlighting the positive aspects of human strength, purpose and potential (Yerxa, 2002). Thus, occupational science can bring a fresh perspective to the rehabilitative needs of people with dementia, and at the same time enhance understanding of ways to support and care for them. Despite a dearth of evidence, the demand for dementia care services is believed to be high relative to other types of service provision (Access Economics Pty Limited, 2008; British Psychological Society & Royal College of Psychiatrists, 2007).

Context of the study

Understanding dementia at this time has to be contextualized in order to grasp the things that have previously influenced understanding and practices. A brief outline of the history of traditional approaches to care will therefore be presented before service provision and policy development within New Zealand is outlined.

Models of care

The literature reveals that the actions of people with dementia are directly related to the care and support they receive (Martin & Younger, 2001). In the past, a diagnosis of dementia was a major reason for admission to custodial care (Cox, 2005). Psychiatric institutions were used for the short term treatment of people with a mental illness, as opposed to an asylum which was intended to be a long term refuge or safe haven for those with chronic mental health issues (Cox, 2005). Over the last 40 years approaches to care of people with dementia has moved through three distinct models.

The institutional model of the 70s and 80s (Taylor, 1987) saw an increase in the number of patients in geriatric hospitals and rest homes. The philosophy of care in these homes was influenced by the doctor/nurse/patient relationships typically found in general hospitals.

Matron was in charge, treatment of illness was the focus, cleanliness and routine was the order of the day. The lower rung of Maslow's hierarchy of needs was the theory applied and restraint was used 'in the interests of the patient'.

During the late 1980s the psychosocial model brought a shift towards increased awareness of social and psychological needs (Kitwood & Bredin, 1992). The traditional concept of service provision prevailed but the need for social and emotional connections was recognized. The link between occupation and health was acknowledged and occupational therapists usually had their own department in geriatric hospitals, church, and charitable trust facilities. Nonetheless, research has shown that residents with dementia did not respond well to these traditional models and care practices as they caused what became known as 'excess disability' (Lucero, 2000). In other words, abilities declined through lack of engagement.

The current model of care, which is based on the introduction of national contract specifications, puts an individual care plan at the core of service provision. This is in keeping with the international change in focus towards person-centred care as advocated by Kitwood (1997). The shift in emphasis from a dependency approach, to care based on personal needs reflects a philosophy of care that seeks desired outcomes. This philosophy represents a significant change in approaches to care for people with dementia. For instance, patients became residents and residents have now become individuals. Each model reflects the knowledge of the time and it would seem that there is greater understanding of the complex needs and abilities of people with dementia.

More recently a combination of approaches is being advocated. Looking beyond person-centred care, literature proposes a relationship approach (Nolan, Davies, Brown, Keady, & Nolan, 2004; Zgola, 1999) and/or the Best Friends approach (Bell & Troxel, 1997, 2003) is more tenable. Each new approach reflects improved knowledge of how to care for people living with dementia. Moreover, there is increasing awareness of the need to acknowledge people with dementia as experts in the field and to learn from them what it means to live with a diagnosis of dementia (Nygård, 2006; Sabat, 2003).

Home care

The ways in which the personal and social costs of supporting a person with dementia are experienced, vary according to individual circumstances. In the early stages many families/whānau manage to cope with the symptoms. As the syndrome progresses, an increased level of support may be required to minimize disability and enhance functional ability (Maddox & Burns, 1997; Ory, Yee, Tennstedt, & Schulz, 2000). Caring for someone with dementia in their own home is reported to be a physically and emotionally stressful task (Jones, 1997; Graff et al., 2006; Mace & Rabins, 2001) as families try to balance the needs of the person with their own needs. Therefore, finding a way to promote a relatively normal lifestyle is essential for the health of everyone concerned. The complexity of individual need requires careful and sensitive investigation, but there is little evidence of such a specific approach in New Zealand.

New Zealand context

Research scientists both here and overseas have highlighted the emergence of Alzheimer's disease as a major economical and social health problem (Alzheimer Scotland, 2006; Ministry of Health, 2002b). International statistics show that specialized services need to be designed to address what is projected to be a rapid increase in our ageing society. Nonetheless, there is little evidence of new initiatives being implemented in New Zealand to offset the projected increase in the number of people living with dementia. In 2006, it was estimated that 24 million people were affected by dementia worldwide (Alzheimer Scotland, 2006). The rate of diagnosis is reported internationally to be one new person every seven seconds, or 1% of people at 60 years, with the figure doubling with each additional 5 years of age. Consequently, experts suggest that by 2040 there will be over 80 million people in the world living with dementia as the number of people with dementia is predicted to almost double every 20 years (Alzheimer Scotland, 2006; Alzheimer's Australia, 2005). Here in New Zealand, the recent economic impact of dementia report commissioned by Alzheimers New Zealand indicated that nearly 45,000 people are currently living with dementia and the number is expected to rise to nearer 75,000 in less than 20 years (Access Economics Pty Limited, 2008). To compound the problem, Alzheimers New Zealand (2005) claimed that for every person diagnosed with dementia there are at least another six to eight and sometimes 10 lives affected when family members and other carers are included.

Government policy

The New Zealand Government's Positive Ageing Strategy (Ministry of Social Policy, 2001) proposed a number of principles in its vision for positive ageing including: "Ageing is a positive experience, regardless of gender, age, culture, or ability" (Ministry of Social Policy, 2001, p. 13). Growth in the number of people living into older age has significant policy implications, especially for Western nations that tend to view older age as synonymous with ill health and cognitive decline (Hughes, Louw, & Sabat, 2006; Wilson, 1991).

Addressing the community care needs of people with dementia (young and old) is a particularly urgent challenge to social policies which, according to Cox (2005), "reflect the values and prevailing ideologies of a society while also providing a framework for services" (p. 40). Cox (2005) further argued that policies are not designed for individuals but for groups of people who share a common problem. Support for Cox' assertion comes from epidemiological studies which group people together in a 'one size fits all' approach, and rob them of their individuality (Ritchie & Lovestone, 2002). History has shown this type of approach does not work because the needs of all older people, not only those with dementia, are individual and complex (Cox, 2005; McIntyre & Atwal, 2005).

Nonetheless, current policy in New Zealand, which promotes the idea of 'ageing in place', in other words in the community, tends to support the 'one size fits all' approach which implies all older people can live independently (Gee & Davey, 2006). Diverging from this attitude, Gee and Davey (2006) suggested that older people should be assessed for services on the basis of their individual circumstances, not on the basis of assumptions. This has particular significance for people with dementia because as Anthony (1996) reported, people differ in terms of their symptoms. Further, he claimed that in the past dementia care was not considered an essential component of community health services. Assumptions like this have a very real impact on policy development as policy-makers at all levels make decisions based on the information they receive (Wilson, 1991). Equally, the implementation of new policy initiatives requires a group of responsive providers (Howe, 1997) since the ways in which the personal and social costs of dementia are experienced in New Zealand in the future will depend on policy developments.

One outcome of the current policy in New Zealand as elsewhere, is that most of the social and economic burden of caring for people with dementia falls on family/whānau and friends because they are the main source of support (Banerjee, et al., 2003). This contrasts greatly with the medical costs of treating people with cancer or cardiovascular disease which are borne by the health service. It has been reported in Scotland that the direct costs to society of caring for people with Alzheimer's disease exceeds the combined cost of heart disease, cancer, and stroke (Alzheimer Scotland, 2006).

Health service policies

Government strategies, such as the Positive Ageing Strategy (Ministry of Social Policy, 2001), are seeking to change the way care services are delivered to older people. However, little is being done to address the specific needs of people with dementia. At their conference in 2007, Alzheimers New Zealand Inc. lobbied the health minister of the time Pete Hodgson, during their opening address, to have Alzheimer's disease recognized as a major health concern. Hodgson (2007) declined, stating that dementia would not be prioritized in the health portfolio as dementia is already a component of the Health of Older People's Strategy (Ministry of Health. 2002a). More recently, at a special Parliamentary function to launch Alzheimers New Zealand's Inc. National Dementia Strategy (May, 2010), the current health minister, Tony Ryall, acknowledged that dementia will be a key issue in the future of New Zealand, however, he also declined to make the condition a health care priority. Nonetheless, demographic trends indicating that New Zealand will see an increasing number of people affected directly or indirectly by dementia highlight gaps in health services, and challenges for service provision.

Many desirable changes can be found by looking at the range of support services available for people with dementia overseas. Countries such as Scotland, England, Canada, Australia, Sweden, Denmark, and Holland have addressed issues arising in both professional and policy forums. These countries are finding innovative ways to support people with dementia and their families. Alzheimer Scotland has made considerable progress in the last 20 years and a range of specialized services are being provided to people living with dementia and their family/whānau in the community (Jackson, 2000). The Dementia Services Development Centre (DSDC) at the University of Stirling provides a strong base of support. Established in 1989, the sole purpose of the DSDC is to extend and improve

services for people with dementia, their family and other carers. Likewise, in Australia, the development of dementia care services is being enhanced through improvements within existing services, as well as setting up specialized services (Alzheimer's Australia, 2005).

In 2006, the New Zealand Handbook SNZ HB 8134.6 *Best practice guidance for community services for people with dementia and proposed audit workbook* was published by Standards New Zealand on behalf of the Ministry of Health. The workbook contains recommendations specifically aimed at improving the quality of care available to people who live with dementia in the community, however the guidelines are, at best, a voluntary course of action. As a member of the committee developing this document, I know a fundamental concern of members was how to ensure service providers compliance with the guidelines. The committee had concerns that the inadequate funding allocated to organizations responsible for the community dementia care sector would make it difficult to implement the recommendations in the workbook and in so doing to achieve the standard. The committee's concern highlights awareness of the gap between the proposed standards and the realities of service provision in the community.

Community-based services

As far back as 1987, Taylor identified the need to improve and expand community-based services in New Zealand to cope with the psychosocial consequences of dementia. Furthermore, he recognized the frustration and anger that was manifest, not only in people with dementia, but also their family/whānau, given the lack of helpful services to offset debilitating symptoms. Research shows that the majority of people living with dementia are cared for in the community. Family/whānau carers are indispensable to a person with dementia, if s/he is to live in the community so the physical, mental, social, and emotional implications of caring must be considered.

Research funding has not been a driving force in developing community services in New Zealand (Perkins, 2004). Indeed finding the appropriate place of responsibility in government policies for the care of people with dementia is complex. This concern is particularly applicable to younger people diagnosed with dementia, as responsibility for those under 65 seems to be divided between various service providers. For instance:

1. Between specialist and generalist care;

2. Between family and health providers;
3. Between institutional and community care; and
4. Between formal and informal care (Howe, 1997).

Social stance and attitudes

For many years, pervasive beliefs in society have been influenced by the negative aspects of Alzheimer's and similar diseases (Bryden, 2002; Taylor, 2007). It is vital to understand the impact of these beliefs, and wherever possible, to change the attitudes that are borne in them. As a result of poor understanding in society, attitudes towards people who live with dementia have been shaped by the idea that it entails the loss of all mental faculties (Hughes, Louw, & Sabat, 2006; Taylor, 2007). Such beliefs influence the way people respond to those who live with dementia and often the person is treated as if they know nothing and can do nothing. Pessimistic attitudes such as this can easily become a self-fulfilling prophesy (Zeisal, 2005) as Western societies value people who are competent, capable, and perceived to be independent, more highly. People with dementia cannot live up to this expectation alone because without help, a progressive decline in cognitive functioning reduces their confidence and thus, their ability to do normal daily activities.

Despite the negative attitudes that surround them, the functional ability and well-being of people with dementia can be maintained, especially in the early stages (Nygård, 2004). Family is well placed to facilitate this, if motivated, but they may not understand the process of dementia sufficiently to provide effective help. Memory impairment does not affect the whole person. For example, if a person cannot remember details of an event then they cannot be expected to relate to the event. However by itself, that does not render the person incapable of doing other things like making decisions about a specific course of action or taking part in familiar, and unfamiliar, activities. While the notion of disability cannot be denied, it is important to recognize that people with dementia retain many abilities. A positive attitude can support and encourage the use of those skills and abilities. These are the skills gained throughout their lifetime and usually include a combination of physical, mental, and social abilities.

A more hopeful perspective

As a result of my work with Ana, I know that personal characteristics and values often remain intact as cognitive abilities decline. Learning about Ana's life history during the

early years I worked with her facilitated person-centred care. This knowledge was crucial in helping her to retain a sense of identity. The continuous modification and adaptation of her own routines allowed Ana to maintain abilities and sustain self image. Prior to the onset of dementia she was self sufficient and had lived life, more or less, to suit herself. It was obvious she was used to having authority and could be quite determined to do things her way. She would often use her initiative to manage difficulties she was having and in this way preserved a sense of competence and control. For that reason, when caregivers tried to change the way things were done, I insisted on Ana's established routines being upheld. Maintaining her routines and habits gave a familiar structure to the day which enhanced her self confidence and thus her dignity and self respect.

Dignity

Dignity is described as an essential aspect of being human (Arino, 2001). Acquired through life experiences, culture, education, social background, and family networks, dignity influences attitudes, values and principles (Mairis, 1994). Respecting and preserving Ana's personal values and beliefs was a key component of her care. Despite deteriorating cognitive abilities, Ana was still able to use skills she had learned in her lifetime. Her memory was 'flaky' and her knowledge of what happened moments before could be elusive, but for a long time, she continued to do what she could for herself to the best of her ability. She would get herself up and dressed in the mornings. When caregivers arrived to help her, she would laughingly tease them by saying she'd "*been waiting for hours.*" She knew her environment so well that she could make her way to the toilet, kitchen, and studio by instinct. In fact, she was still drawing portraits at the age of 88. Not regularly by any means, but if she could get someone to sit for her she would become absorbed in this satisfying task which she said gave her "*immense pleasure.*" Respecting her right to do things her way meant she was afforded the dignity of self-determination. This, in turn, ensured she retained the ability to enjoy doing things, feel emotions and to express feelings, laugh and have fun. I believe utilizing these abilities enabled Ana not only to maintain a sense of identity, but to live with dignity. I also believe both these concepts contributed to her quality of life.

Quality of life

According to Sarvimäki (1999), when health and functional ability can no longer be restored the focus turns to quality of life. By the time I came to know her, Ana's quality of

life had been eroded by the fact that she had few friends, partly because of her age, but also because of her condition. In one instance a friend went so far as to say it was no fun to visit her anymore. They had known each other for over 60 years but he couldn't bear to be with her "*since she lost her mind.*" As visits from others who were still alive and able became less and less frequent, she told me more than once that because she was "*a sickly child*" she had to learn to endure loneliness and so she became an avid reader. In older age, when her ability to read or do other things was declining, she visibly thrived on the company of others, and yet she became socially isolated because of her dementia. Friedell (2002) suggested that quality of life is an individual matter which depends on personal choice. Given that active participation and interpersonal connections were very important to Ana, I suspect that loneliness detracted from her quality of life.

The lessons I learned from Ana are important. While I know people have diverse ideas on quality of life, and no two people will have the same goals, as an occupational therapist, knowing is not enough; I wanted to understand more fully what can be done to promote active participation in occupations and social connections for people with dementia. Oakley (1992) encouraged the use of research to achieve such goals when she stated "the primary end of scientific research is not knowing but understanding" (p. 344). When I reflect on the ways in which people with dementia have traditionally been cared for, I am convinced that as a society, we can do better.

Clinical practice

Based on this belief, I promote modification, adaptation, and participation in daily activities in clinical practice. People with dementia are often deprived of opportunities to engage in daily occupations because it is assumed they can no longer participate. On the contrary, giving them the opportunity to use existing skills helps them retain abilities. When working in residential care, I carefully gather an in-depth personal history of each resident and share it with staff. The information gathered can then be used by staff to enable the resident to use their abilities. My goal is to facilitate a sense of well-being by supporting residents to engage in normal daily occupations that will help them maintain a sense of competence and fulfillment that cannot be achieved by any other means.

In the community, goals which emphasize independence for people with dementia are unrealistic, because they are in conflict with the disease process. This is especially true if there is no basic understanding of what is required to allow the person with dementia to function with some degree of autonomy. However, encouraging people to engage in daily occupations can help them to retain abilities. Furthermore, studies have shown that community occupational therapy can improve the functional independence of people with dementia and decrease the burden on the caregiver (Dooley & Hinojosa, 2004; Graff et al. 2006). For reasons such as this, I encourage people to maintain a balanced lifestyle by engaging in a range of physical, mental, and social activities.

Rationale for the study

As this discussion has revealed, the occupations and participation of people with dementia is a complex issue requiring further study. The rationale that lies behind my reasons for doing the study is more straightforward. My experience with Ana, as outlined in the preamble, gave me an insight into the ways in which the symptoms of dementia are manifest and shaped by outside forces. I know the impact a diagnosis of dementia can have on people's lives. In my work as an occupational therapist in residential care, I see first-hand the decline that robs people not only of their memories but of their identity, dignity, and quality of life. These concepts are all inter-related and my understanding of them, and their place in the life of people with dementia, is addressed in the context of this study.

Belief in the importance of enabling people with dementia led me to select an action research methodology for this project because it allows collaboration with participants. Action research is a scientific method of inquiry that has evolved as a 'family of approaches' (Reason & Bradbury, 2006). These approaches belong within the realm of the qualitative research paradigm and, as with other forms of qualitative research, pre-understandings around the question need to be identified from the beginning. As Merriam (cited in Creswell, 1998) pointed out "it is important that the reader understands the researcher's position and any biases and assumptions that impact in an inquiry" (p. 202). Put simply, my assumptions about supporting people with dementia have been shaped by my personal experience. Flexibility and openness to other people's point of view, which are a way of life for me, are also important features of action research because they help to

ensure that the results of the study are an accurate reflection of the interaction between researcher and participants.

There is little common agreement on the essential features of action research, however, it is generally accepted within social and health research that the research design and methods are derived from the research question and aims, rather than guided by a particular worldview (Carr & Kemmis, 1986). For some, action research is primarily grounded in the scholarly traditions of knowledge generation, while for others; action research is a way of taking action to improve learning with social intent (McNiff & Whitehead, 2006). Such is the purpose of this study. Linked with social change for social justice, this research is not simply about problem-solving but about learning and creating knowledge. Action research has its roots in critical theory, but where critical theory looks for understanding in order to bring about change, action researchers go into action to create change. So action research is undertaken for two main purposes:

1. To contribute to new practices (this is the action focus of action research).
2. To contribute to new theory (this is the research focus of action research).

The emphasis is always on how the researcher can make a difference for good through the practice of action research and, while it may be undertaken by individuals, action research is always a participatory and collaborative process rather than individualistic process. Therefore, to inform and facilitate change in current practices that will support people with dementia to engage in daily activities, this study aims “to explore and address the interconnections and tensions between system and life world aspects” (Kemmis, 2006, p. 101) of living with dementia. Consequently the research was designed to:

- Identify and define broadly applicable approaches that will enable people with dementia to participate successfully in daily occupations in the New Zealand context.
- Influence the attitudes of family/whānau and others about the potential for people with dementia to participate in daily occupations.
- Support implementation of government policy on positive ageing by generating knowledge and identifying services required to support people with dementia and their family/whānau caregivers.

Summary

This chapter has introduced the purpose of the study, why it is important, and the construction, contexts, and the concepts considered significant. The method of inquiry which encourages action learning through a cyclical process of gathering evidence and testing theories in action while looking for a new way of seeing and understanding an issue, has been introduced. Underpinning the study are values and principles that allow new meanings to be explored and new ways of seeing to be developed in partnership with participants.

The literature is reviewed in chapter two. In my search for information and understanding, I have read widely to review the current body of knowledge, establish what is known (and thereby what is not known) nationally and internationally about the research topic. Books, research articles, and feature articles from a variety of sources are discussed and critiqued in relation to current occupational science literature that emphasizes the importance of understanding the human as an occupational being.

Within chapter three the philosophical stance and methodology are discussed. Chapter four addresses the methods used to undertake the research. Ethical considerations are recalled, and recruitment methods, the number of participants and their demographic information such as age, and personal background are disclosed. The types of questions used in the discussions with participants are outlined and summarized. Finally, the data analysis process is presented before chapter four concludes with a discussion of issues of rigour.

The results of the study are presented in chapters five, six, and seven, followed by the discussion, recommendations, and conclusions in chapter eight. The action component of this study will be a work in progress to further increase understanding. This is but one thoughtful attempt to develop understanding of the connection between occupation, participation, and people with dementia and their family/whānau, all the while knowing that no single study will ever achieve final answers.

Chapter Two

Literature Review

“The important thing in science is not so much to obtain new facts as to discover new ways of thinking about them”

William Lawrence Bragg (1890-1971)

The quotation above suggests that knowledge can be enhanced if we look beyond that which is known, to reflect, question, modify, and amend our thinking and reach a new understanding. Keeping this thought in mind while searching the literature on Alzheimer’s and other types of dementia should help to uncover new possibilities and to expose new ways of understanding how people who live with dementia in the community can be supported to engage in daily activities.

Examining the literature is a necessary pre-requisite to any research project, to learn more of the topic being explored and to place the study in the context of that which is already known. There is a profusion of literature by academics from a broad range of disciplines, and others, who have written about dementia (Anthony, 1996; Barnett, 2000; Clare, 2003a; Nygård, 2004; Small, & Perry, 2005; Woods, 1999a). Not all of the available information is relevant to this study and whereas I initially gathered an overwhelming amount and read widely, I soon came to realize that I needed to refine my search. Given my commitment to hear the voices of participants in the early stages of dementia about their daily activities living in the community, I specifically wanted information about engagement in occupation. My experience of working with Ana, coupled with predictions of a potential onslaught of people diagnosed with dementia, convinced me that more could and should be done to improve their lives. Proxy reports done by health professionals and academics have not improved social understanding and management of the condition. What better source of knowledge development than learning from people whose daily life in the community is affected by dementia? Accordingly, that is where the review of literature starts.

The pursuit of new ideas to enhance the lives of all people who live with dementia is a persistent challenge to modern science (Shenk, 2001). Therefore it is valuable to examine developments in knowledge over time. Moreover, to gain a wider perspective, information

from various disciplines including the social sciences, psychology, psychiatry, medicine, and occupational therapy needs to be reviewed. In presenting an account of the history of ideas that surround approaches to caring for people with dementia, the debate around listening to people with dementia is considered, their support needs are explored, current interventions are outlined, and broader health care concepts examined.

Voices of people with dementia

People with dementia have historically played a passive role in investigations of their condition (Phinney, 2008; Wilkinson, 2002). These days there is international recognition that people with dementia are quite capable of reporting their unmet needs (Bryden, 2005; Nygård, 2006; Phinney, 2008; Pratt, 2002; Reid, Ryan, & Enderby, 2001; Sabat, 2003). This shift in thinking acknowledges people with dementia as experts of their own experience. Rather than being relegated to the receiving end of care services, people with dementia are breaking new ground when they contribute to the creation of knowledge. Similarly, family/whānau members who play a vital role in supporting the person with dementia in the community have an important contribution to make (Banerjee, et al., 2003; Dooley & Hinojosa, 2004). The significance of this will become increasingly relevant as the generation commonly known as ‘the baby boomers’², reach retirement age (Gee & Davey, 2006). The anticipated surge in the number of people living with dementia has alerted health professionals to the fact that more insight into the experience of dementia is needed if health and social services are to meet their needs in the community (Gitlin & Corcoran, 1996; Innes, Archibald, & Murphy, 2006). Still, trusting that people with dementia have the ability to convey their experience and to participate in the determination of needs is subject to ambivalence.

Issues of trust

On one hand, Reid, Ryan and Enderby (2001) warned that the very nature of dementia means that listening to the people who live with the disease is fraught with dangers. Some people will recognize their declining abilities, others will not. Therefore they suggest that the person’s ability to make decisions must always be in doubt. On the other hand, they go on to argue that researchers must err on the side of capacity. Likewise, Darzins (2005) advised that the decision-making capacity of people with dementia is a legal construct. Just as all people are presumed innocent until proven guilty, it is a basic premise that people

² People born between 1946 and 1967

with dementia must be presumed to have presence of mind (Gregory & Lough, 2003). Bryden (2005) endorsed this stance when she claimed that “we [people with dementia] have full capacity until it has been proven otherwise” (p. 130). Furthermore, these opinions are supported by the World Health Organization’s (1978) declaration at Alma-Ata, which decreed that “people have the right and duty to participate, individually and collectively, in the planning and implementation of their health care” (p. 1).

While some researchers question the reliability of self-report by people with memory deficits (Katsuno, 2005), others argue that if researchers are to obtain an insight into how people with dementia experience their lives, then those people must be included as informants in the research process (Nygård, 2006; Sabat, 2001). The ability to self-reflect is usually lost early in Alzheimer’s disease for psychological reasons, both mental and emotional, rather than irremediable neurological reasons (Friedell, 2002). Indeed, research has shown that some people in the early stages of dementia struggle with some aspects of memory while others remain relatively intact (Clare, 1999; Snowden, 2001). In fact, the findings of two longitudinal studies indicate that a variety of highly complex cognitive abilities can exist in some people with dementia, despite the fact that they were in mid-to-late stages of the disease (Sabat, 2003; Snowden, 2001).

This shift in thinking towards the capacities of people with dementia is important because it has been argued that they are one of the most excluded groups in Western society when it comes to health care (Phinney, 2008; Wilkinson, 2002). The fact that people with dementia are often excluded from consultation processes because it is assumed they are unable to take part is a prime example (Shenk, 2001). In addition, they are subject to a double jeopardy, that of being older people as well as, people with a cognitive disorder (Post, 2000; Wilkinson, 2002). With current moves in policy and practice emphasizing social inclusion and justice for older people (Ministry of Health, 2002a, 2010; Wilcock, 2006), it is necessary to redress these imbalances. In recent years many relevant scientific and social changes have occurred and it is no longer tenable for people with dementia to be represented by proxy voices or to have decisions made on their behalf by health professionals.

Classifying dementia as a disease category has had an important impact on the way society views people with dementia. Even though the first case of dementia was written up in the early 1900s (Shenk, 2001), it was not until the mid-1970s when demographic trends and an ageing population became a concern, that the financial significance of dementia brought closer attention to the disease (Wilkinson, 2002). This rise in interest was reflected in a corresponding increase in dementia research. The main focus of the research was the cause of, or cure for the disease. Understanding of the process tended to be grounded in a medical model, which dehumanized people with dementia rather than treating them as individuals with a health problem (Zeisal, 2005). This social construction by medical professionals has effectively upheld the stigma associated with dementia. Furthermore, it is the basis of excess disability and unequal relations that have marginalised people with dementia (Sabat, 2003).

A research approach aimed at reducing this traditional stereotype needs to bring about a fundamental change in the way dementia is perceived, so that the experiences of those who have it are seen to be valid and their behaviours driven by meaning (Sabat, 2003). Action research, a process that alternates continuously between inquiry and action as part of the research process, is increasingly being used to develop health care services that are responsive to the populations they serve (Munn-Giddings, McVicar, & Smith, 2008). A systematic review of research papers undertaken to gain insight into the amount of practice-based action research being published in nursing research found a total of 62 articles deemed suitable for analysis (Munn-Giddings, McVicar, & Smith, 2008). Of those, only 13% were considered 'clinical' while 87% involved organizational and/or professional development or educational settings and in 90% of the studies the main participants were practitioners. The point is, despite its potential to bring about change for service users, action research appears to have been predominately used to focus on changing the practices of health professionals. Few of the reported studies included service users in the research process.

Challenging the medicalised view of dementia using a more person-centred approach is perhaps the first step towards building services and policy that will address and respond to individual needs and experiences (Wilkinson, 2002). Of note, when searching electronic databases such as AMED, EBSCO HOST, and OVID for the purposes of this literature

review, only one article was found using the keywords dementia, person-centred care, and action research despite repeated calls for in-depth action research involving service users (Meyer & Sturdy, 2004; Munn-Giddings, McVicar, & Smith, 2008; Perrin, 1997a).

Shifting perspectives

Whereas the initial clinical assessment of people exhibiting cognitive decline is usually medically focused, central to the assessment process are deficits in social and occupational functioning (Anthony, 1996; Wilkinson, 2002). In recognition of this fact, there is a discernible shift towards taking a broader perspective of the impact that dementia has on a person's life and health (Post, 2000; Standards New Zealand & Ministry of Health, 2006). This may be why the literature advocated that diagnosis should be done by a multidisciplinary team including a psychiatrist, neuropsychologist, occupational therapist, and social worker (Anthony, 1996; Pangyres, 2003; Sabat, 2003). The literature also stressed the importance of assessing a broad range of factors in search of a potentially treatable cause for the decline. Once a diagnosis of neurological degeneration is established, a systematic approach to care management is strongly advocated (Clare, 2003b; Pangyres, 2003; Ritchie & Lovestone, 2002). Moreover, both Decker (1996) and Sabat (2001) recommended that the person with dementia should be included in a consultation process with all team members to decide individual needs and potential.

With all the emphasis on the diagnostic process, there has been a tendency to ignore and/or minimise problems following diagnosis while focusing on the hopeless nature of dementia (Iliffe, Eden, Downs & McRae, 1999; Post, 2000; Snyder, 1999). This sense of hopelessness is evident in an article written nearly 30 years ago which claimed "dementia is a form of dying" and more "the task of the therapist, care-giver, or companion of the dementing person is to help in the dying process" (Symonds, 1981, p. 1709). This pessimism existed at a time when early diagnosis was not possible. Nonetheless, the pervasive tendency to focus on the negative outcomes of dementia prevails (Bryden, 2002; McKillop, 2002). Until recently, drugs were commonly used to manage unusual behaviours (MacDonald & Teven, 1997). Now, people who have written about their experience of living with dementia are voicing their scepticism about the use of drugs (Bryden, 2002; Friedell, 2001; Taylor, 2007). This stance is increasingly supported by evidence which indicates that psychotropic drugs are unsafe for people with dementia (Ballard, Margallo-

Lana, Juszczak, Douglas et al., 2005; Banerjee, 2009; U.S. Food and Drug Administration, 2005). Research has found that the risks of side effects such as over sedation causing an increased risk of falls, postural hypotension, akathisia or motor restlessness and agitation, tremor, and drooling outweigh the benefits (Aschenbrenner, 2005; MacDonald & Teven, 1997; Salmon, 2006).

In contrast, recent studies undertaken with people in the early stages of dementia strongly suggest that the social, practical and physical aspects of health are important facilitators of a healthy lifestyle (Clare, 2003b; Dabbs, 1999; Sabat, 2003) while the idea of rehabilitation following a diagnosis of dementia is increasingly promoted in literature (Anthony, 1996; Clare, 2003b; Gregory & Lough, 2003; MacRae, 2007; Öhman & Nygård, 2005; Shenk, 2001). This vision is strongly supported by authors who have written from personal experience (Bryden, 2002; DeBaggio, 2002; Friedell, 2001 & 2003a; Taylor, 2007). These authors, who were all diagnosed with dementia at a young age, have argued that rehabilitation will give people with dementia hope for the future. Amongst them, Friedell has perhaps been most vocal in the professional literature however, it was DeBaggio (2002) who advocated:

Doctors and advocates can help, but there is nothing like personal stories to humanize the silent, destructive power of this illness. The more we talk about it and expose Alzheimer's, the greater the chance a cure will be found quickly. (p. 141)

Loss of hope

There is currently no hope of a cure and success of treatment is debateable (Taylor, 2007) so loss of hope is a common theme in dementia (Warrington, 1996). When writing about their experiences, both DeBaggio (2002) and Taylor (2007) reported that cognitive deficits impacted on their self-confidence and this ultimately led to a withdrawal from other activities, and depression. Similarly, Bryden (2002) stated that the anticipatory loss of self is a cause for grief and fear, and the prospect of what might lie ahead is depressing. People who are depressed are known to be prone to excess disability. According to Friedell (2003a), when “the psychological trauma of a catastrophic illness is combined with negative or patronising attitudes (or fear of those attitudes, or both)” (p. 2) then it follows that excess disability is inevitable. This process has been outlined by Zygola (1999):

Because a person's initial disability makes it difficult for her to interact effectively with a conventional environment, her behaviour becomes anomalous and efforts to do things are often unsuccessful. Repeated failure and frustration eventually cause her to

stop doing things and interacting with people. This leads to social isolation and sensory deprivation, which in turn results in more anomalous behaviour, more deterioration in function, and even greater social and sensory deprivation. So it goes in an ever-downward spiral until the person's functional decline far exceeds the effects of the original disability. (p. 209)

In his book *Man's Search for Meaning*, Victor Frankl (1964) argued against losing hope. Rather he claimed that the meaning of life is found in every moment of living, "life under any circumstances never ceases to have a meaning, and that this infinite meaning of life includes suffering and dying" (p. 83). Frankl concluded that a person's psychological reactions are not solely the result of the conditions life has imposed, rather they also stem from the freedom of choice one has even when suffering. The innate hold a person has on his spiritual self relies on having faith in the future and when faith is lost, hope is lost. Thus, Frankl advocated that spirituality is closely related to hope.

Interventions aimed at improving function have the potential to reduce secondary problems such as loss of spirituality, and to give people hope for the future, both the person with dementia and their family/whānau (Clare & Woods, 2004). Recently, both researchers and people living with dementia have challenged the view that people with dementia lack insight, ability and judgment among other cognitive abilities. Furthermore, they bemoan the notion that the rehabilitation available to people who have had a traumatic brain injury is untried on people with dementia (Bryden, 2002; Clare, 1999, 2002; Friedell, 2000; Shenk, 2001). For instance, Friedell (2000) argued that if people with a brain injury can benefit from rehabilitation, why not people with dementia? "We are supposed to be unable to learn, but we are notorious for developing the social skills to mask our deficits" (Friedell, p. 1). Still more researchers have shown that the ability to take part in familiar activities requiring memory and judgment is often retained well into the disease process (MacRae, 2007; Sabat, 2001; Snowden, 2001).

Rehabilitation

The idea of a professional rehabilitation programme for people with dementia is tantalising (Shenk, 2001). In advocating for rehabilitation, Friedell (2000) did not envisage overcoming decline with brain exercises as others have suggested (Macey, 2006; Editorial, 2006). Rather he argued that the ultimate mortality brought about by the disease should not automatically eliminate people from the hope of living a full life, for the longest time

possible. Instead of taking a passive approach to managing loss, Friedell (2000) structured a personalised programme designed to minimize, and slow, cognitive decline through doing what Shenk (2001) termed “meaningful life tasks” (p. 96). Friedell’s (2000) theory encompassed a basic rehabilitative concept of relearning activities using a greater number of easier steps. However as Shenk (2001) pointed out, slowness in any aspect of daily social life can cause problems. Nevertheless, current research has outlined strategies by which people with dementia construct meaningful lives despite the challenges cognitive decline presents (Clare & Woods, 2004; Graff et al., 2006; MacRae, 2007; Wood, 2005). For instance, the cognitive rehabilitation approach (Clare & Woods, 2004) is designed to make the most of remaining abilities by identifying ways of retaining important information or real-life practical skills. To reduce the demands on memory, this approach looks for ways to compensate for difficulties by using strategies such as memory aids or modifying the environment (Dooley & Hinojosa, 2004; MacRae, 2007; Moore, Sandman, McGrady, & Kesslack, 2001). Graff et al. (2006) found that occupational therapy intervention in the community is a highly effective non-pharmacological therapy for people with dementia and their caregivers. Improved outcomes for both included daily functioning, sense of competence, quality of life, mood, and health status. Friedell’s (2000) theory, which supports Frankl’s (1964) ideas on spirituality, is upheld by this early research.

Spirituality was central to Friedell’s (2000) initiative. The concept of spirituality, in this context, refers to the worldview of the person, place, and time. Spirituality has an important role to play, both in rehabilitation and in maintaining an identity reflected in personal history. The importance of a person’s spirituality in coping with the experience of dementia was also a key factor of Kitwood’s (1993b, 1997) work. He highlighted the connection between the manifestation of dementia and personal belief’s, personality, biography, health, neuropathology, psychological status, and the social environment. Although Kitwood (1997) predominantly focused on people in residential care, his ideas on caring illustrate a practical approach to which everyone can relate (Woods, 1999b).

Characteristics of care

The strong body of academic work developed by Kitwood (1997) and other researchers from various professional disciplines has focused on the individual needs of the person

with dementia (Clare, 2003a; Graff et al., 2006; MacRae, 2007; Martin & Younger, 2001; Morton, 2000; Sarvimäki, 1999; Wood, 2005; Woods, 1999a). Building on the idea that caring is an interpersonal process, Kitwood (1997) proposed the idea of ‘person-centred care’ in the belief that more can be done to help the person experiencing cognitive decline to maintain a sense of health and well-being than has previously been understood. In addition, he claimed that attributing the unpredictable behaviour of people with dementia solely to the disease process is incompetent (Kitwood, 1993a).

Furthermore, in terms of the social context, the social stigma attached to a diagnosis of dementia has been claimed to be a result of poor knowledge, uncertainty, and “malignant social psychology” (Kitwood & Bredin, 1992, p. 271). This stance was endorsed by Post (2000) who stated that “the moral challenge of being with AD (Alzheimer’s disease)...requires that we overcome the stigma associated with dementia, principally by being with deeply forgetful persons in attentively caring ways that draw upon their emotion, relational and creative capacities” (p. 3). Although the issues of cost and distributive justice are very real, to achieve Kitwood and Bredin’s (1992) vision, there is a very great need in New Zealand society to develop a culture of dementia care (Perkins, 2004).

Insights from people with dementia

The reality of being cared for has been addressed by authors who write from experience. In his book *Losing my Mind*, De Baggio (2002) frequently referred to the impact of his diagnosis on his wife and family. Sensitive to their distress, in his opinion they “suffer...an excruciating torture” (p. 135) watching him decline. Having to turn to them for comfort and help, knowing they are “battered by worry” (p. 135) about the future, was deemed to exacerbate an already challenging situation. When writing about his son De Baggio (2002), noted that he would always be haunted by the fear of also becoming a victim of young onset dementia. Similarly, when referring to his wife, De Baggio (2002), reported that the diagnosis “sent her reeling emotionally” (p. 130). De Baggio (2002) described his wife’s depression as she struggled to come to terms with his diagnosis and all that it entailed:

No one could have prepared her for the struggle I have presented her...I slapped her with a large emotional hurdle, my slow, wretched death by Alzheimer’s. I cannot know her pain except as she has allowed me to see it. (p. 145)

This is not unusual and has been corroborated by other authors who have written about a “period of darkness” (Snyder, 1999, p. 40) that descended following a diagnosis of Alzheimer’s or similar type disease. Similarly Richard Taylor (2007), a retired psychologist, wrote about his family’s experience of dealing with the disease: “Most families, like ours, keep trying until we get it approximately right and hope we have not alienated each other in the process” (p. 167).

Dimensions of care

The majority of people living with dementia are cared for in the community. A survey done in the UK found that only about half of those are known to service providers (Banerjee, et al., 2003). Similar trends are likely in New Zealand. When exploring the meaning of the caring role in relation to dementia, research from various academic disciplines has focused on the problems, the burden and strain associated with caring, and the physical, psychological and social costs (Mace & Rabins, 1999; Millán-Calenti, Gando-Crego, Antelo-Martelo, López-Martinez et al., 2000; Philp, McKee, Meldrum, Ballinger, Gilhooly, et al., 1995). Caring for someone with dementia in the community is assumed to be more difficult and oppressive than caring for someone with other chronic conditions, yet there is little evidence to verify this belief (Ory, et al., 2000; Philp et al., 1995).

Nonetheless, the past 20 years of descriptive research has established that family caring is an onerous duty with high costs to the person doing the caring (Schulz, 2000). From this we can deduce that the caring relationship is a social construction with a material basis that can become oppressive (MacRae, 1995). Conversely, MacRae (2007) noted that other possible interpretations or dimensions of caring have received less attention. For example, the idea of an ethic of caring was put forward by Wright-St. Clair (2000) who suggested that the notion of caring has the potential to inform “the meaning and experience of relating human to human” (p. 23). Further, she defined caring as an attitude that grows over time from an inherent capacity to respond to the needs of others.

Family relationships

Many families/whānau are reluctant to relinquish their caring role and put off having a loved one admitted to care. However, the very nature of the disease-process coupled with the lack of support often leaves them exhausted and prone to ill-health (Millán-Calenti et al., 2000; Morrish, 1999). Consequently, as a result of the emotional strain, social isolation,

and economic repercussions, it is reported that family relationships deteriorate (Millán-Calenti, et al., 2000; Sainsbury, 1997). Providing residential care for people with dementia is known to be a high health expenditure (Perkins, 2004), and research has shown it is not necessarily the best option (Butler, Fonseca, Barclay, Semblie, et al., 1998; Chung, 2004; Lintern & Woods, 2000). Nevertheless, community services to assist people with dementia and their families/whānau are scarce in New Zealand (Perkins, 2004).

Faced with insufficient community support, families/whānau are often at a loss to understand changes in behaviour and acknowledge the stress that invariably occurs when they find themselves struggling to understand the person's needs along with other demands (Snyder, 1999). The extent to which caring affects the physical and mental health of carers is an important issue. Equally, the lack of appropriate services is a key concern from the perspective of people with dementia, especially younger people (Royal College of Psychiatrists, 2000).

Differing needs of people with young onset dementia

Young onset dementia refers to a progressive degeneration of the brain cells before the age of 65. The use of 65 years of age for young onset is arbitrary but widely employed in western societies to differentiate between younger and older people. Dementia is rare in people under 65 but still, people who are diagnosed before that age are psychologically unprepared for such an event. A dementia affecting people in their 40s, 50s, and 60s will present challenges that are more debilitating than an older onset dementia. For instance, the clinical progression of young onset dementia is faster than older onset dementia. Ultimately, it is a terminal illness for younger people but not necessarily so for older people (Harris & Keady, 2004; Kay, Forster, & Newens, 2000; Luscombe, Brodaty, & Freeth, 1998; Tindall & Manthorpe, 1997; Williams, Keady, & Nolan, 1995). Once diagnosed, a younger person with dementia lives an average of 8 to 10 years (Keady & Nolan, 1994; Ritchie & Lovestone, 2002). In contrast, people over 65 can live up to 20 years and more after onset (Tindall & Manthorpe, 1997).

Contrary to popular belief, Alzheimer's disease is not the most common cause of young onset dementia (Harris & Keady, 2004). Rather it can be caused by neurodegenerative, autoimmune, or inflammatory conditions such as Huntington's disease, Frontal lobe

dementia, Lewy Bodies disease, and Human immunodeficiency virus (HIV). The symptoms of these diseases may differ from the more common causes of dementia in older people, such as Alzheimer's disease, vascular dementia, and Parkinson's disease (Harris & Keady, 2004; National Collaborating Centre for Mental Health, 2007). Even when Alzheimer's disease is the cause of young onset dementia, the symptoms and progression may differ between young and older people (Kay, Forster, & Newens, 2000).

The problems faced by younger people vary from those of older people because they are usually physically fitter, and experience greater emotional turmoil (Barber, 1997). They struggle to find a reason for cognitive decline, unlike older people who can blame age and stage in life. In addition, younger people have an added frustration inasmuch as dementia affects employment opportunities (Reed, Cantley, Clarke, & Stanley, 2002). Anecdotal evidence from Cox and Keady (1998) provided a strong message that younger people want to remain part of society for as long as they can, living a normal life with roles and responsibilities that are age-appropriate.

Regardless of the stated desires of people with younger onset, research shows that dementia in younger adults has long been under resourced in most countries and in addition, younger people with dementia are neglected by health service providers (Panegyres, 2003; Royal College of Psychiatrists, 2000; Sainsbury, 1997; Williams, Keady, & Nolan, 1995). It is particularly difficult for younger people to be accepted as disabled when appearing physically fit (Tindall & Manthorpe, 1997). Reports show that available services are unsuited to younger people's needs and this ultimately causes management issues (Barber, 1997; Reed et al., 2002). Of the many difficulties associated with young onset, prominent among them is the fact that available care services are predominantly designed for older people (Reed et al., 2002; Royal College of Psychiatrists, 2000). Analysis of existing specialist literature revealed again, that most studies are rooted in the medical model of health (Bryden, 2002; Luscombe, Brodaty, & Freeth, 1998; Panegyres, 2003; Tindall & Manthorpe, 1997) which means they focus on managing symptoms and charting the progression of the disease, rather than on how people can be supported to live meaningful lives.

Studies suggest that the complexity and cost of supporting younger people with dementia are disproportionate to the number of people with the problem (Kay, Forster, & Newens, 2000; Keady & Nolan, 1994; Tindall & Manthorpe, 1997). Nevertheless, the Clive Project in Oxfordshire, England, provided valuable insights into the needs of younger adults with dementia. This home-based service was specifically designed to support the younger person on their own terms, accepting and understanding limitations caused by the disease process (T. Gutteridge, personal communication, June 1, 2004). Similarly, the Younger Person's Project in Glasgow, Scotland, made the case for separate services for younger people by identifying the differences between their needs and those of older people. The project did not replace an existing service, rather new interventions were developed and delivered at the same time (Alzheimer Scotland, 1998).

Overview and critique of interventions

Listening to people with dementia has helped to shape knowledge of interventions that meet their needs and varying abilities (MacRae, 2007; Snyder, 1999; Wilkinson, 2002). Much-needed attention is being given to what has become known as the behavioural and psychological symptoms (Ritchie & Lovestone, 2002) and academics from various disciplines agree that many promising research avenues have yet to be explored (Clare, 2003b; Friedell, 2003a; Sabat, 2003; Snowden, 2001). Interestingly, some researchers advocate that a sense of normality can be facilitated when a variety of interventions are combined with knowledgeable caring (Clare & Woods, 2004; Ritchie & Lovestone, 2002; Salmon, 2006; Zeisel, Silverstein, Hyde, Levkoff, Powell Lawton, et al., 2003). The pharmaceutical industry, with the support of health professionals and people with dementia, insist that drugs can help to preserve functional abilities (Salmon, 2006), and this despite the fact that there is increasing evidence indicating that drugs do not slow progression of the disease (Ballard et al., 2005; O'Brien, 2008; Saul, 2007).

Pharmaceuticals

People with dementia and their family/whānau are said to be desperate for some way to treat the symptoms of Alzheimer's and similar type diseases (Saul, 2007). This is apparent in the amount of money spent on drugs. In the USA alone it is reported that \$1.4 billion is spent annually on drugs that have yet to be proven effective (McNee, 2005; Saul, 2007). When the British National Institute for Health and Clinical Excellence (NICE) recommended withdrawal of subsidies for cholinesterase inhibitor drugs for people with

moderate Alzheimer's disease, based on cost effectiveness, the suggestion was greeted with outrage across England and Wales (Leading Edge, 2006). NICE claimed that the practical effectiveness of the drugs, which cost £2.50 per person per day (Alzheimer Scotland, 2006), remains controversial. The decision to veto the supply of drugs was appealed in England and Wales. In the interim, Alzheimer Scotland (2006) successfully lobbied the Scottish Executive and National Health Service to ensure that the same edict was not enforced in Scotland.

For a long time, PHARMAC, the New Zealand government's drug-buying agency, refused to fund the group of drugs known as cholinesterase inhibitors, arguing that the evidence to justify spending money on these drugs was getting weaker, not stronger (McNee, 2005). Nevertheless, PHARMAC recently announced its decision to fund a brand known by the generic name of Donepezil to be known as *Donepezil-Rex* once it is registered by Medsafe (Moodie, 2010). This drug, an acetylcholinesterase inhibitor which is said to enhance cognitive function, is also known by the brand name *Aricept*. The results of a five-year double blind study found that *Aricept* is largely ineffective in delaying progress of the disease or entry into a rest home (Banerjee et al., 2003). In a report prepared for PHARMAC, McNee (2005) suggested that the money would be better spent on social support for people with dementia and those caring for them. Alternatively, Clare (2003b) advocated that drug treatments may be useful in the early stages of dementia when coupled with cognitive training designed to help with memory problems.

Alternative interventions

The debate around the benefits of drugs has increased awareness of the need to find ways of maintaining cognitive function, or at least helping people who are currently living with dementia. According to an Editorial in the New York Times (December 27, 2006), dozens of studies have investigated the latest American trend which is said to slow deterioration of mental faculties – brain health programs, or brain gyms. 'Maintain your brain' workshops and 'Love your brain' brochures are being promoted to offset decline (Belluck, 2006). The Editorial (December 27, 2006) also reported that science is not sure yet whether the hopes for brain health programmes are realistic or whether they will improve ability to tackle daily activities but there are encouraging hints in the data. Stronger evidence comes from the recently released findings of an Australian study which indicate that complex mental

activity across the lifespan almost halves the incidence of dementia (New South Wales Office for Science and Medical Research [OSMR], 2006).

Equally, the cognitive benefits of keeping physically active have been well documented (Loland, 2004; Manini, Everheart, Patel, Schoeller, et al., 2006), with older people who engage in physical exercise scoring better on mental tests than those who do not (Roan, 2006). According to a recent study which focused on Alzheimer's disease and the ageing brain, there is proof that physical exercise actually creates new nerve cells in the area of the brain that affects memory decline (Carmichael, 2007). Dr Scott Small, Associate Professor of Neurology at Columbia University, is reported to have said "this adds yet another reason to the long list of reasons why exercise is good for overall health" (Carmichael, 2007, p. 1). The results of the study indicated that despite age, a strong, active body is essential for building a strong, active mind. More controversial is the proposal that exercise might slow the progression of Alzheimer's once it has taken hold (Carmichael, 2007).

Despite this accumulating evidence, a team of researchers aligned to the University of Massachusetts, Boston, reported that when faced with a person exhibiting declining cognitive abilities, some physicians feel there is little hope (Zeisal et al., 2003). Still, other international researchers know that a combination of interventions can be used to support people with dementia and protect their functional abilities (Clare, 2003a; McDonald & Teven, 1997; Woods, 1999). This belief is endorsed by occupational therapists and others whose research clearly shows that people with dementia who engage in a variety of physical, mental, and social activities are more likely to maintain skills (Dabbs, 1999; Loland, 2004; MacRae, 2007; Manini et al., 2006; Öhman & Nygård, 2005; Wood, 2005).

Occupational therapy

Occupational therapists have much to offer in the way of interventions for people with dementia (American Occupational Therapy Association (AOTA), 2004). They have the knowledge and skills required to identify neurocognitive impairment through occupational assessment (Robinson & Fisher, 1996). The therapy involves devising interventions which facilitate engagement in daily activities (Anthony, 1996; Salmon, 2006; Wood, 2005). It has been argued that interventions designed to maintain skills and develop abilities to promote autonomy and competence, do help to address the problems that arise from the

symptoms of dementia (AOTA, 2004; Graff et al., 2006; Nygård, 2004; Nygård & Borell, 1998; Woods, 1999b). In the same way, occupational therapists know the advantages of supporting continuity of lifelong occupations (Powell, Bray, Roberts, Goddard, & Smith, 2000), the rewards of using “skills that are relatively well preserved or that use procedural memory” (Öhman & Nygård, 2005, p. 89), the influence of the physical and social environment (Gitlin & Corcoran, 1996; Letts, Rigby, & Stewart, 2003), and the implications of values and beliefs with reference to identity and well-being (Christiansen, 1999). Furthermore, occupational therapy knowledge has proven efficacy in achieving significant gains in physical health, social functioning, vitality, mental health, and life satisfaction in older people (Clark, Azen, Zemke, Jackson, Carlson, et al., 1997).

The connection between occupation and health is also acknowledged in the WHO’s Ottawa Charter of Health Promotion (1986) which states that “health is created and lived by people within the settings of their everyday life” (p. 3). When people are engaged in a meaningful occupation, in doing something they enjoy, their mind is focused on what they are doing, and brain cells are firing because the person is active and involved (Clark et al., 1997). From this perspective, occupation is central to functioning, health and well-being. The social benefits are similarly important. Research has shown that being part of a group, be it a gardening club, a football team, or a walking group, gives people a sense of identity and fulfillment (Jackson, 1996). Maintaining health through a balance of daily occupations helps people with dementia to use their remaining abilities and retain some control over their lives (AOTA, 2004). Likewise intervention to prolong people’s autonomy by enabling them to construct a healthier, more positive lifestyle will have a positive effect on their self image (Sabat, 2003).

According to Yerxa, Clark, Jackson, Parham, Stein, et al., (1989), one of society’s greatest challenges today is to understand the relationship between engagement in occupation, and health and well-being. For example, the things people do each day, our occupations, shape the way we think of ourselves and present ourselves as competent people (Kielhofner, 1995a). Similarly, our occupations influence the way other people think of us (Christiansen, 1999). In recent years, the academic discipline of occupational science has emerged to support the practice of occupational therapy (Yerxa, 1993). Occupational science is the study of people as occupational beings with an innate need to engage in

occupations (Yerxa, 1993). Occupational scientist's advocate that occupation is not just about doing, being and becoming, it is about belonging and contributing to society (Townsend & Wilcock, 2004). In light of this, the notion of occupational justice is important.

Occupational justice

The concept of occupational justice underpins the belief that recognizing, and providing for, the occupational need of individuals and communities is a step towards healthy living in a fair and just society (World Federation of Occupational Therapists, 2006). Occupational justice is bound up in concepts of health and includes the belief that the right to engage in occupations is a matter of social justice (Wilcock & Townsend, 2000). When people are excluded from engaging in "the daily round of work, play, rest, self care, and care of others" (Wilcock & Townsend, 2000, p. 84), whether by regulations, funding policies, fear or stigma, they are deprived of social connections and opportunities to experience competence and success, all of which add meaning to life. Indeed, it is an injustice to have health services which diminish the physical and cognitive capacity of people with dementia through inappropriate use of antipsychotic medications (Ballard et al., 2005; Salmon, 2006). The same can be said of services which predominantly focus on supporting carers when there is a dearth of services directed towards supporting people who actually live with dementia.

In relation to occupation, justice is about enabling alternative opportunities to engage in occupations. The World Federation of Occupational Therapists (2006) upholds this stance in its Position Statement on Human Rights where it claims: "People have the right to be supported to participate in occupation and, through engaging in occupation, to be included and valued as members of their family, community and society" (p. 1). This means having social policies that will add depth and meaning to life by encouraging active participation in wide-ranging occupations for people of all ages, without discrimination (Wilcock, 2006). The literature claimed that regardless of a person's ability to participate in daily activities, their sense of well-being which includes identity, dignity and quality of life should always be considered and respected (Gabriel & Bowling, 2004; Gallagher, 2004; Sarvimäki, 1999).

Concepts of well-being

There is compelling evidence that subjective concepts of well-being such as identity, dignity and quality of life are critical aspects of caring for a person with dementia (Chung, 2004; Nygård, 2004; Nygård & Borell, 1998; Wood, 2005; Woods, 1999a; Yerxa, 1998). Whereas cognitive decline may appear to be the result of just another disease, especially for older people, De Baggio (2002) stated “it is unique...because it destroys the mind without which you lose your sense of being human” (p. 142). Essentially De Baggio (2002), is referring to the ability to remember our human identity, our sense of being in the world. Identity, which has been linked to psychological well-being, is not a moment frozen in time; rather it is an evolving process from which we create our sense of self, our unique personality (Kaufman, 1986; Taylor, 1989). Maintenance of dignity is also emphasized when considering the health and well-being of people with dementia (Banerjee, 2005; Sabat, 2003). Any threat to dignity is a threat to the person’s self-worth (Campbell, 2006), just as a threat to self-worth is a threat to identity (Christiansen, 1999).

Identity and dementia

Research focused on the relationship between concepts of health and occupation (Clark et al., 1997; Clark, Jackson, & Carlson, 2004) has reported that engagement in meaningful activity is perhaps the single, most important attribute affecting older people’s attitude to health. People who have a sense of purpose in life feel good about themselves and this in turn enhances the way they think of themselves, their self-image (MacRae, 2007; Sarvimäki, 1999). In fact, it is said that personal identity is shaped through everyday occupations (Laliberte-Rudman, 2002; Taylor, 1989; Yerxa, 2002).

The concepts of identity and self-image are useful to improve understanding of the experience of dementia. According to Hogg, Terry and White (1995), identity is a social construction. When we come into this world, we are known only as the child of our parents. With the passage of time we develop a personal identity through the things we do, the decisions we make, and individual traits including our personal attitudes, feelings and behaviours. Additionally, social identities evolve through group affiliations (for example, Pakeha or Māori) and the social roles we occupy (for instance, mother or father) (Hogg, Terry, & White, 1995). Stryker and Burke (2000) suggested that identity can be both stable and fluid over time. In other words, a person has past and current identities. Alternatively,

Laliberte-Rudman (2002) reject identity as a passive, static structure, arguing instead that it is an interpretive, socially-constructed postmodern concept deriving from interaction between person, occupation, and environment.

Several assumptions about identity form a connection to continuity theory (Kaufman, 1986), a central construct of which is the maintenance of valued occupations, roles and interests over time (Laliberte-Rudman, 2002). The theory has significance for people with dementia as it is widely understood in society that they will lose their identity. Continuity theory stresses the importance of preserving a constant sense of self across the life span and yet, paradoxically, later life has been constructed by society as a time of decline and withdrawal (Kaufman, 1986). Researchers in the field of occupational science advocate that continuity of meaningful occupations is a key to physical and psychosocial well-being (Clark, Jackson, & Carlson, 2004; Jackson, 1996; Yerxa, 2002). In addition, research has found that people tend to age more successfully when they remain connected with who they have always been (Mandel, Jackson, Zemke, Nelson, & Clark, 1999). Maintaining a sense of continuity and meaning has been found to enable older people “to cope with change and thus, is a critical resource for remaining healthy” (Kaufman, 1986, p. 6).

Analysis of the literature shows that the concept of identity has received wide attention in the social sciences from many perspectives and has been studied as both an objective reality (what it is) and a process (how it operates) (Rieber, 1998; Taylor, 1989). While some theorists link identity to the things people do (Christiansen, 1999; Laliberte-Rudman, 2002), others view it in broader terms consisting of multiple layers of meaning that are cultural, structural, social and individual in origin (MacRae, 1995; Reiber, 1998; Stets & Burke, 2000; Taylor, 1989). The constructionist view was sanctioned by Sabat and Harré (1992) when they claimed that the writings of the well known philosopher Ludwig Wittgenstein (1889-1951) and the establishment of developmental psychology by Lev Vygotsky (1896-1934) inspired recent advances in the theory of linguistics in relation to identity. Similarly, Sabat and Harré (1992), argued that language is central to the development of social reality, including how people’s identity is perceived, because people use speech to articulate their thoughts and experiences. Language has also been identified as playing an important role in attitudes and practices of inclusion and exclusion (Blot, 2003; Habermas, 1984). The link between language, individuality, and social development

reveals much about identity in relation to the debilitating symptoms of dementia. DeBaggio (2002) reinforced this notion when he explained that as a result of declining abilities he reached a stage whereby he no longer considered himself competent to speak in social settings: “I have become comfortable to sit in a room with people conversing and listen silently” (p. 201).

The loss of self which characterizes dementia brings about an identity crisis that can profoundly affect the person’s actions (Bryden, 2005; Stets, & Burke, 2000). DeBaggio (2002) referred to this when he stated: “In its early stages, when you are most sensitively aware, you watch as you slowly lose yourself. Memory disappears, language is gone, you forget who you are and become lost and dependent” (p. 142). Similarly, the ways in which other people view and respond to people with dementia contributes to their loss of identity (Sabat & Harré, 1992). Bryden (2005) confirmed this when she explained that following her diagnosis: “No one knew what to say, what to expect of me, how to talk to me, even whether to visit me. I had become a labeled person, defined by my disease...no longer able to function in society” (p. 156).

There is a dialectical relationship between self-image and social image when a person’s memory of their personal history is affected (Clare, 2003a). This social constructionist theory proposes that our self-image requires the mutual cooperation of others. Although Sabat and Harré (1992) argued self-image does not hinge solely on social cooperation, there is a strong link between people’s ability to gain approval from others and their ability to portray themselves as competent people (Christiansen, 1999). Here again DeBaggio (2002) provided an example when he stated: “I am lonely in my dead life. Even when I am with people and laughing with them, I am alone, isolated from the normal world, unable to remember this morning, constantly trying to remember the moment just past” (p. 200).

Experiences such as this support Kaufman’s (1986) theory of continuity in that people need to show, through the ability to engage in former pursuits, that they are still the same person they had always been. This suggests that any threat to a person’s ability to engage in daily activities becomes a threat to their identity. Once a person is deemed to be confused or incompetent, it is difficult for their actions to be seen in any other way (Sabat & Harré, 1992) and for this reason it is necessary to protect their self respect and dignity.

Dignity and dementia

Considered a basic human right, dignity is inextricably intertwined with respect, although an exact definition is hard to find. Many philosophers and health professionals have attempted to define dignity and put it into context (Gallagher, 2004). The Canadian philosopher, Charles Taylor (1989), wrote of dignity as “the characteristics by which we think of ourselves as commanding (or failing to command) the respect of those around us” (p. 15). Similarly, Haddock (1996) claimed that essentially dignity is the ability to feel confident and valuable in relation to others. Described as an inherent characteristic of being human, and a dynamic personality trait, dignity includes taking pride in oneself and showing respect for others (Jacelon, Connelly, Brown, Proulx, & Vo, 2004). Additionally, Christiansen (1999) suggested that dignity is achieved through competence in the performance of daily activities. Although the Western world espouses the values of dignity and respect, people with dementia do not always inspire respect because of their perceived loss of intellect and memory (Post, 2000). Bryden (2005) confirmed this when she stated:

One day I hope we [society] will treat people with dementia with respect, recognize how hard they are trying to cope with getting through each day, and provide them with appropriate emotional support, social networks, and encouragement...there are 24 million people around the world who are living with dementia, who are worthy of respect. (p. 11)

The need to treat people with dignity and respect is receiving greater attention in ethical debate globally (Campbell, 2006). The importance of treating people with dignity and respect has endured as a core value in the health professions (DiBartolo, 2006) and indeed is considered a duty in professional codes of conduct. For instance, the code of ethics drawn up by the Occupational Therapy Board of New Zealand (2004) stated: “Occupational therapists shall demonstrate that the dignity, privacy, safety, health and concerns of people receiving their services are important and respected” (p. 3). Further, Article 1 of the Universal Declaration of Human Rights (1948) (UDHR) states: “All human beings are born free and equal with dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood” (p. 2).

The concept of dignity also features in national legislation within the field of health care. For example, standard 1 of the Health and Disability Service (Core) Standards (Standards New Zealand & Ministry of Health, 2008) states: “Consumers are treated with respect and

receive services in a manner that has regard for their dignity, privacy, and independence” (p. 7). This goal is supported by the Positive Ageing Strategy outlined by the Ministry of Social Policy (2001). In analyzing the concept of dignity, Campbell (2006) advocated that everyone is entitled to live life to the best of their ability and feel like a valued human being. Friedell (2003b) endorsed this principle when he stated that “it is time for the cognitively-impaired to cast off their shame, come out of the closet, and fight for their dignity” (p. 1). Anything less is not an option if the goals of the Health and Disability Service (Core) Standards (Standards New Zealand & Ministry of Health, 2008) are to be achieved and people with dementia and their family/whānau enabled to enhance their quality of life by living with dignity.

Quality of life and dementia

When it comes to quality of life there is little agreement about its relationship to health (McKevitt, Redfern, LaPlace, & Wolfe, 2003). For many years, health professionals and social researchers have argued over what constitutes quality of life (Albert, 1998; Campbell, 1976; Frank, Kleinman, Kline Leidy, Legro, & St Dennis Revicki, 1998; Gabriel & Bowling, 2004; Leplège & Hunt, 1997). According to Campbell (1976), it is connected to a person’s life experience and therefore in essence, is a subjective concept based on personal opinion. From a medical point of view, quality of life is measured in terms of physical function/dysfunction. However, some researchers claim that these measures do not capture the multidimensional aspects of quality of life (Leplège & Hunt, 1997). They fail to take into account all the possible interconnections between medical, non-medical, and individual factors that play a role in the complex relationship between the potential determinants of health and quality of life (Leplège & Hunt, 1997).

Quality of life takes on a new meaning when health and functional ability start to deteriorate (Sarvimäki, 1999). Recently, the concept of quality of life has attracted interest and development as an outcome measure in the assessment of health care services (Moyle, McAllister, Venturato, & Adams, 2007). Yet the multifaceted nature of quality of life is not addressed in the traditional health-related models used in the assessment process (Gabriel & Bowling, 2004), although it is clearly important in a chronic disorder such as dementia. To achieve a better understanding of quality of life, it is necessary to move beyond health and functional status (Leplège & Hunt, 1997). This may be why social gerontologists have

argued that the notion of quality of life is not purely an objective or subjective construct. Rather it is unique to individuals and encompasses the classic understandings of physical and psychological well-being, along with autonomy, social connections, and life satisfaction (Gabriel & Bowling, 2004). Accordingly, the World Health Organization (WHO, 1997) defined quality of life as: “A broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to the environment” (p. 1).

Studies have shown that the things people consider relevant to determining their quality of life vary with age. Younger people prioritise work and finances whereas older people indicated that factors such as health, home and family, social contacts, activities, and meaning in life were more important (Cox, 2005; Gabriel & Bowling, 2004; Puts, Shekary, Widdershoven, Heldens, Lips, & Deeg, 2007). Speaking for people with dementia, Friedell (2002) endorsed the WHO definition when he stated that “quality of life is an individual matter, which partly depends on what sort of life the person considers meaningful” (p. 361).

Quality of life has become a focus of inquiry in dementia research (Innes, 2003; MacRae, 2007) and is increasingly advocated in the literature as a way of incorporating service users’ perspective (McKevitt, et al., 2003). Capturing the opinion of people who live with dementia is essential to develop an understanding of their experience rather than continuing to think of the disease process as an inevitably “slow death” (Katsuno, 2005, p. 198). People with dementia can, and do, maintain quality of life (Bryden, 2005; Friedell, 2002; Katsuno, 2005; Sarvimäki, 1999; Strecker Neufeld, 2004) but its significance depends on the individual perspective. For instance, Friedell (2002) suggested that being able to reflect on life, to participate in and enjoy a special moment with a loved one, and to have hope for the future are key factors in quality of life. According to Friedell (2002), the number or size of experiences is not essential; it is the capacity to enjoy simple pleasures which constitutes quality of life. Friedell (2002) went on to say that the greatest challenge to quality of life for people with dementia is “the darkness of the future” (p. 360). Several authors who have dementia reported that living without hope for the future means living with a sense of dissatisfaction in general (Bryden, 2005; DeBaggio, 2002; Friedell, 2002; Taylor, 2007).

Research by academics from various health disciplines has established that life satisfaction contributes to quality of life (Dooley & Hinojosa, 2004; Gabriel & Bowling, 2004; Glass, Mendes de Leon, Marottoli, & Berkman, 1999; Moyle, McAllister, Venturato, & Adams, 2007). Promoting a satisfactory life and thus quality of life by keeping people with dementia in their own home is in accord with the current promotion of positive ageing in New Zealand (Ministry of Social Policy, 2001). People with dementia are often more competent at home (Dabbs, 1999; Sarvimäki, 1999) because they can use “automatic pilot in familiar environments” (Nygård & Öhman, 2002, p. 76) to help them do routine activities. The term ‘automatic pilot’ in this case refers to “subconsciously employed strategies” (Nygård, 2004, p. 43) or abilities that have been called into action so many times in the person’s lifetime they have become embodied. Utilizing existing abilities enables people with dementia to enjoy a sense of competence and they are more likely to respond well to daily tasks and occupational challenges when they are performed in familiar surroundings (Nygård, 2004; Strecker Neufeld, 2004). Studies have found that the level of satisfaction gained from participation in daily activities is directly related to a positive attitude and feelings of well-being (AOTA, 2004; Jackson, 1996).

Summary

This review has provided a background against which the views of people with dementia can be researched. In turn, this endorses the entry of this marginalised group of people into the mainstream of research and practice, and as a result the research process will be more informative. The decision to take a person-centred, action research approach, so that people with dementia can contribute to discussions of their support needs, has been supported.

The concepts of care revealed in the literature tend to be based on other people’s ideas around the needs of people with dementia. In order to increase understanding of what it actually means to live with dementia it is imperative to ‘hear’ the voices of people who live with a disease that causes dementia. Capturing their experiences, views, and opinions frames them as potential contributors to wider debates, including policy debates.

The literature also shows that as yet there is no effective long-term treatment and/or intervention for people living with dementia. Consequently, it is essential to focus on concepts of health as a means of moving on from the assessment process to explore other

meaningful ways of supporting them. The occupational view of humans as occupational beings who benefit from engagement in daily activities was outlined, so actions consistent with occupational justice will help to develop social awareness of individualistic concerns for quality of life, dignity and respect.

In this context, action research is an appropriate methodology to explore the question of how people with dementia who live in the community can be supported to engage in daily occupations. The goal is not to determine what people with dementia can do, but rather to help devise further questions and strategies for action, with a view to discovering new ways of thinking about people's capacity and need to engage in occupations, despite a diagnosis of dementia. The next chapter will consider the philosophy which informs the methods used to answer the research question.

Chapter Three

Philosophical and Methodological Underpinnings

“Every great advance in science has issued from a new audacity of imagination”

John Dewey (1859-1952)

How does audacity of imagination relate to this study, I wonder? For me it is about moving the discussion of the marginalized areas of dementia research, policy and practice, from a neglected position to one of inclusion. This study seeks to contribute to progress by looking for possibilities, exploring what is, and imagining what could be.

The stigma and stereotypes associated with a diagnosis of dementia imprisons people with ideas of who they are and what they are able to do. This sets them apart from the rest of society because other people make assumptions about their abilities. There is a sense that stories about dementia are harmless (Hughes, Louw, & Sabat, 2006) because some form of cognitive decline is thought to be inevitable in older age. However words, labels, and attitudes have a profound effect on both individual and societal perceptions and these in turn, impact on the ability of people with dementia and their family/whānau to carry on living a normal daily life. As the incidence of dementia increases, there is a need to change the way society responds to, and supports, people who live with cognitive decline. Improving society’s perception of brain disease processes and their effects, by generating new knowledge of ways to support people to engage in daily activities, may help to bring about change because poor understanding at the societal level erodes people’s ability to live life with a sense of purpose, dignity, and self respect.

Since my intention was to include people living with dementia as participants in a research process designed to generate knowledge that will challenge the way society perceives and responds to them, a participatory action methodology was initially thought to be most appropriate. The participative worldview sees human beings as co-creating their reality through participation, drawing on their experience, their insights and intuition, their thinking and their actions (Park, 1993; Reason, 1994). However, with increased understanding of the various forms of action research, I came to recognize that fully

implementing a participatory action approach was not possible in this study. Participatory research is an interactive and dialectical process in which the researcher and the participants work together (Park, 1993) to find solutions to common problems. From this, a particular type of knowledge is generated. One of the interests guiding this study was to understand how people with dementia can be supported to engage in occupations in the context of taken-for-granted assumptions, practices, and ideologies. Since people with dementia were not initially involved in the research planning, it was necessary to use traditional methods of recruitment and data gathering before a collaborative process could begin. Action research offered a way forward in this regard.

Habermas's (1984) theory of communicative action further helped to enlighten me on social theory and after reaching a new understanding, I decided to reframe the research methodology as a critical approach to action research. Before entering further discussion of the methodology however, the philosophical underpinnings of the research process are presented to give a sense of direction and proportion (Carr & Kemmis, 1986).

Philosophical base

Although there is no simple definition, philosophy is traditionally understood to deal with three key questions: What exists? How do we know? What are we going to do about it? The answers to these questions involve ethics, how one should live; metaphysics, the study of the nature of reality; epistemology, what counts as knowledge; and logic, what are the principles of interpretation? While some argue that philosophy has a lot to do with deep logical thinking and rationalizing the conclusions drawn, others argue that philosophy is best defined as an attitude or way of life (Gadamer, 1998; O'Hear, 2001; Sherratt, 2006; van Manen, 1990). Distinctive in a critical view is a refusal to go along with social norms without some reflection on the ways of life (Habermas, 1984; Stangroom & Garvey, 2005).

Philosophers have long debated the distinction between the natural sciences (positivist) and the human sciences (interpretive). One school of philosophy (Anglo-American, positivist) tended to look at the natural sciences as the model of inquiry and the benchmark of truth, while the other (European, interpretive) pursued a critique of normality in search of authenticity. Some philosophers believe that human reality is too diverse to be confined to one truth so both schools of philosophy offer lessons worth learning (Gadamer, 1976;

Habermas, 1984; Lewin, 1948). For the purposes of this study, and in the tradition of philosophers who learned from those who had gone before, I looked back for guidance on how to move forward. It was important to me to know enough about philosophical traditions, without becoming a professional philosopher in an academic sense, to more fully understand how best to re-configure that which is known, to support this study.

In offering a philosophical justification for the belief that people with dementia and their family/whānau have a special role to play in this study, I was drawn to European philosophy, in particular critical hermeneutics as presented by Kögler (1999). Essential to this discussion is an explanation of how critical hermeneutics can be used to challenge and extend the current understanding of the nature of dementia. Hermeneutics is a human science approach to research which is deeply rooted in philosophy (van Manen, 1990). Knowing that it is defined as a specific theory of interpretation, traditionally used to reach an understanding of someone else's point of view, it seemed an ideal theoretical framework for seeking to understand how people with dementia who live in the community can be supported to engage in daily activities. Action research is commonly underpinned by critical social theory and this approach was initially considered. However, given that the purpose of the study was to explore issues of power and occupational justice from the perspective of people with dementia, interpretation of the data required a theoretical approach that could make sense of the discussions and observations so as to convey understanding. On this issue Kögler (1999), presented a model of hermeneutic meaning formation that shows how social power practices are capable of shaping symbolic assumptions and understandings of people and society.

Kögler (1999) claimed that critical social theory, philosophical hermeneutics, and discourse analysis are compatible. In his book 'The Power of Dialogue' he argued that Habermas's version of critical theory can be transformed into critical hermeneutics using Gadamer's philosophical hermeneutics and Foucault's studies of power and discourse as a framework. Kögler (1999) proposed a balance between Gadamer's perception of interpretive dialogue, with its strong focus on individual self-understanding, Habermas's concern with ideologies, and Foucault's theories on the structure of discourse and the practices of power. Kögler (1999) does not necessarily support the distinction between philosophical hermeneutics and critical social theory; rather he uses the hermeneutic notion of pre-understanding and the

subjective nature of interpretation to bring together the critical tools of discourse analysis and the microanalysis of social power practices. By means of a “methodologically undogmatic amalgam of interpretively gleaned insights and conclusions, phenomenological observations, and analytically conceived results and arguments ... the underlying premise of ... interpretive praxis” is revealed and brought to consciousness (Kögler, 1999, p. 11). In the pages that follow, I will discuss critical social theory before presenting an overview of the work of Habermas, Gadamer, and Foucault to explain the ways in which it has shaped and informed the critical hermeneutic stance taken by Kögler (1999).

Critical social theory

Critical theory has two quite different meanings with different origins and histories, one originating in social theory and the other in literary criticism. In sociology and philosophy the term, said to be derived from the critical theory of Marxism (Agger, 1991), is a critique of society and culture. In contrast, Habermas (1971) introduced critical theory as a form of hermeneutics. That is to say, a critique of knowledge gained through the interpretation of texts. Until recently these two meanings had little to do with each other, but since the 1970s there has been some overlap between the disciplines. This has led to critical theory becoming an umbrella term for an array of theories in English-speaking academia giving rise to diverse explanations of the term. To some, it is first and foremost an attempt to overcome some of the weaknesses of Marxism, while others perceive it to be a part of a longstanding dispute about hermeneutic philosophy. Still others see it as an attempt to synthesize neo-Wittgensteinian philosophy with European philosophy (Carr & Kemmis, 1986).

The critical social theory relevant to this study has its origins in the Frankfurt School. Named because of its location, the school comprised an interdisciplinary group of academics who were opposed to the reigning tradition of logical empiricism. Influenced by a plethora of social thinkers from Ancient Greek philosophers to orthodox thinkers of modern Germany, scholars at the Frankfurt School believed that bringing different disciplines together would yield insights that were unobtainable by working within narrow and increasingly specialized academic domains. Thus they challenged the widespread assumption of the time, that the empirical approach of the natural sciences was the only valid one (Finlayson, 2005). The difference between natural science (positivist) and human

science (interpretive) relates to what is being studied. According to van Manen, (1990) natural science considers *objects of nature, things, natural events* and *the way objects behave*. In contrast, human science seeks to understand *people*, or beings that have *consciousness* and that *act purposefully* in and on the world by forming *meanings* in life that are *expressions* of how human beings continue to live in the world (van Manen, 1990).

Understandably then, critical social theory is grounded in the problems of everyday life (Carr & Kemmis, 1986) and thus forms a basis for action research in that it was constructed with a view towards solving social problems. Of significance is the way in which critical theory has shaped the idea of critical social science with a view to the theory-practice relationship. Essentially, like action research, critical theory is social theory oriented toward critiquing and changing society as a whole. It differs from positivist and interpretive social sciences which are oriented only to explaining or understanding practice. In this study, the critical thrust aims to promote social awareness of the abilities of people with dementia. The goal is to challenge the social inequalities and oppressive ideologies that are sustained and produced by similar institutional social structures and ideologies as those critiqued by Habermas (Hoy, 1982).

Habermas

Known as a leader of the second generation of Frankfurt School theorists, Habermas's work is best understood as an ongoing response to the critical theory of the first generation of Frankfurt School theorists. Habermas developed the idea of a critical social science to overcome the limitations of social theory. His intention was to locate social theory between philosophy and science (Carr & Kemmis, 1986). Using a synthesis of French and German approaches to social theory, Habermas and others argued that diverse theoretical and empirical approaches are needed to support informed social criticism because neither empirical analytic (natural science) nor interpretive (human science) approaches to research has an explicit politics (Reason, 1994). Habermas's (1984) work differed from that of his Frankfurt School mentors in that his deep concern for individual freedom was always linked to a keen interest in the structure of a democratic society. He focused on the importance of communication in human interactions because he believed that poor communication was the root of society's (major and minor) problems. Habermas's

argument is given credence in the social stigma that surrounds the common view of dementia.

Accordingly, for Habermas, critical theory had to say something about the value of ideologies which shape people's understanding and in so doing identify the social and political conditions that foster distorted self-understandings. Of key concern was the process of shaping public opinion and ideas on how rational discussion was possible in a modern, developed society. He argued that critical theory is associated with communication and emancipation. It is a form of knowledge that serves to free people from the bureaucracy which dominates society (Sherratt, 2006). Habermas placed a great emphasis on three forms of knowledge: the productive (technical), the communicative (language), and the emancipatory. He postulated that technical interest is the focus of the natural sciences, practical interest is incorporated into hermeneutics or the human sciences, and emancipatory interests can be found in the critically oriented sciences (Habermas, 1971). One of the principal issues uniting all of his theories is how knowledge is related to human social activity (van Manen, 1990).

Habermas believed that human beings interpret the world around them through activities, both mental and physical, and thus critical social science was practical, not just theoretical. The goal was to reach an understanding of specific issues in society and then use the knowledge generated to help transform social and political conditions for the better. However, a tension in the epistemology of critical social science between the epistemic advantages of a single, inclusive theoretical framework and those of methodological and theoretical pluralism remained problematic (Carr & Kemmis, 1986). By shifting the focus, as argued by Kögler (1999), Habermas's version of critical theory is transformed into a new critical hermeneutics that builds on both Gadamer's philosophical hermeneutics and Foucault's studies of power and discourse.

Gadamer

Gadamer was a German philosopher who devoted a scholarly lifetime to the exploration of human understanding and interpretation. His thinking was moulded through dialogue with thinkers from the past as well as those from his time (Gadamer, 1998). Gadamer developed a conception of human understanding which took into account the ways in which the

interpreter may be influenced by time and place in history. In so doing he argued that methodological questions pertaining to scientific understanding have distorted the hermeneutical experience in its universality. For Gadamer (1976) the task of philosophical hermeneutics is to throw light on the essential conditions that underlie understanding in all its modes, scientific and non-scientific alike, and to present understanding as an event over which the interpreter only has partial control. There is however, a choice to remain open to new fusions of understanding and thus for the evolution of human understanding.

Like Habermas, Gadamer criticized the use of scientific methods as the only route to establishing truth. He was critical of modern approaches to the humanities that modeled themselves on the natural sciences. Furthermore, he was dissatisfied with traditional hermeneutic philosophy which advocated that correctly interpreting text or traditions meant recovering the original intention of the creator. In contrast to both of these positions, Gadamer insisted on the role of 'living language' in understanding, even in the understanding of written texts (Palmer, 2001). He proposed that written language is perpetuated by living language:

The meanings of all presentations fixed in writing are carried by something else that can only be mediated in living language. Other phenomena participate in the transmission, like urgency, intensity, stronger tone or softer tone, above all, - slight doubt or hesitation. (Palmer, 2000, p. 391)

Thus, Gadamer advocated that the problem of understanding involved interpretive dialogue that is always rooted in the tradition of the interpreters.

Gadamer (1998) argued that people always have "historically effective consciousness" (p. 28) which is grounded in their own personal history and the particular traditions to which they have been exposed in life. He also recognized the possibility of a blending or a 'fusion of horizons' when human beings participate in the hermeneutic act of interpretation of the conversations, texts, and traditions of others. In this way, Gadamer provided a descriptive analogy of how different perspectives can come together to reach understanding both dialectically and dialogically, through the use of language and conversation. According to Gadamer (2001), understanding is always an interpretation, and the relationship between the two is dynamic and reciprocal. Interpretation facilitates understanding and understanding requires interpretation.

Explaining how all interpretation is derived from an intrinsic understanding, or prejudgment that is neither prejudiced with self-meaning nor a generalisable process, was Gadamer's most significant contribution (Wood, 2003). Understanding, from Gadamer's perspective, refers to the historically and culturally situated traditions which influence both humanity and language. Gadamer argued that the interpretations derived from such understandings always involve a mingling of the familiar and unfamiliar, and his model for the way understanding leads to interpretation is dialogue, or conversation. Gadamer claimed that people pre-understand themselves and their world through linguistically acquired consciousness, and observers of people must treat these pre-understandings, and their own, as necessary ingredients of social inquiry. Thus, his ideas have linked European philosophy with the Anglo-American tradition. Philosophical hermeneutics in Gadamer's sense is one of the most effective responses to those who favour reductionism and relativism in the Western philosophical tradition (Wood, 2003).

The possibility of transcending history and tradition in order to find a truly objective position from which to criticize society was debated by Habermas and Gadamer over many years (Scheibler, 2000). The debate, which focused on the construction of knowledge, was a response to the fact that empirical and analytical knowledge was recognized as the only valid form of knowledge at the time. Although the debate was inconclusive, a critical hermeneutics was developed out of the interplay, whereby critical theory informed hermeneutics (Crotty, 1998). In challenging Gadamer's notions of tradition and language, Habermas argued that because of 'systematically distorted communication' the only voices people hear are the ones they inherit via the forces of ideology. According to Habermas, language or discourse is inherited from someone else and it is therefore always tainted by the distortions of power and domination (Habermas, 1984; Lawn, 2006). Although able to accept the reality of dominant forces, Gadamer countered that these can only be understood through language as "power is dependent on communicative agreement" (Kögler, 1999, p. 76). Issues of power bring us to the work of Michel Foucault, who is known for his microanalysis of power practices, knowledge and discourse.

Foucault

French philosopher Michel Foucault was a social critic and historian whose vast influence extended across a range of disciplines, especially the humanities and social sciences.

Through his studies, Foucault absorbed an intellectual atmosphere rich with existentialism, structuralism, and Marxism. German philosophers Hegel, Nietzsche, and Heidegger were huge influences on his thinking before he developed his own opinions. In particular, it is reported that Nietzsche shaped Foucault's conception of society and power. These two concepts form the basis of Foucault's interest in the ways in which knowledge and truth function in social hierarchies of power (Sherratt, 2006). Foucault offered new theories that challenged people's assumptions about social power structures. He is best known for his critical studies on social institutions, in particular psychiatry, medicine, the prison system, and the history of human sexuality (Brown, 2000). Of significance to this study is his well-known reputation for analyses of power, knowledge, and discourse in the human sciences.

According to Foucault, the current forms of daily life are based on a "vast, impersonal and invisible network of power relations" (O'Hear, 2001, p. 8) that traditional concepts of authority are unable to understand and criticize. By means of opinionated and sometimes obscure, (though often interesting) discourse analyses of history (O'Hear, 2001), Foucault tried to convince others that the basic ideas which people normally take for granted as enduring truths about human nature and society actually change over time. While exploring the shifting patterns of power within society and the ways in which power influences people, Foucault studied the circumstances, both micro and macro, under which human beings become the objects of knowledge. He wanted to discover and explain the thinking behind the ideas that rule the human sciences which emerged in the nineteenth century.

Foucault's main method for examining the scientific disciplines, and how they structure the objects of their study, was through discourse analysis. For Foucault, a discourse is a body of text that has a widespread focus of study, a common methodology, and/or similar conditions and ideas (Sherratt, 2006). Discourse analyses allowed Foucault to engage with a broad variety of texts, from different cultures, historical periods, disciplines, and genres (Klages, 2001). For example, the discourse on dementia would include a history of the evolution of understanding dementia, autobiographies of people who live with dementia, accounts by people who care for people with dementia, writings by health professionals who work with people with dementia, and articles by scientists seeking to reveal the cause and a cure for dementia.

According to Foucault, knowledge can be traced to the divergent discourse practices that control information. He made use of everyday experiences and ordinary language to define the limitations of common knowledge. Thus he made a direct practical contribution to social science whilst offering a rich and varied description of how social structures of power, modes of knowledge and practice, were constituted in the past by way of the discourses through which they were manifest. Foucault argued that power operates in and through discourse as the other face of knowledge, giving rise to the term power/knowledge. By putting words to work, discourse gives meaning, shapes perceptions, and creates understanding and ongoing courses of interaction (Gubrium & Holstein, 2000). Foucault's aim was not to denounce power per se nor to propound the truth, but to use his analysis of power, knowledge and truth to show the specific dangers that each type of power and knowledge can produce, and thus to suggest new ways of viewing the social world.

In trying to forge a fusion between the language of philosophy and a scientific understanding of society, both Foucault and Habermas recognized that an understanding of critical reason was essential. However, their understandings of critique and reason were different (Hoy, 1986). Habermas argued that an analysis of the conditions for validating truth was the way to unify critical reason and social concerns while Foucault wanted to be responsive to what is unacceptable in mainstream society by outlining both the general problem and exemplifying a course of action which allowed people to see, through discourse, that there are meaningful differences in the type of society we can have. He advocated that there are some ways of being human that should be opposed and others that should be strengthened. By reconceptualising the ideas of Habermas, Gadamer, and Foucault, Kögler (1999) contributed to the dialogue and debate about the nature of power, knowledge and discourse.

Kögler

Kögler's (1999) approach is reconstructive. He started out by critically analysing the alternative theories and historical antecedents of Habermas, Gadamer, Foucault, and others. Reflecting on social power, Kögler (1999) explored the ways in which meaning is shaped and how the process of interpretation can achieve reflective distance and a critique of power, while influenced by social forms of power. His work offers a unique perspective on issues pertaining to the effect of prejudice and culture on scientific interpretation. He

argued that this can be used to understand others without fully embracing their beliefs or debating the truth of their interpretation.

In defense of this approach Kögler (1999) stated that the paradigms of social science (unlike those of the natural sciences) do not relate to one another as historical successors. Social scientists do not drop one theory in favour of a better one. Rather, reflecting on social theories moves the thinker to a new level of understanding and thus a new level of thinking and seeing. According to Finlayson (2005), one criterion of a good social theory is the degree to which it can engage with its antecedents and competitors, explaining and preserving their successes, while remedying their defects (p. 19). To this end, Kögler (1999) offered a synthesis of theory with systematic intent to explain how the human and social sciences, as practices of interpretation, can contribute to and exemplify or replace what has formerly been understood as a critical social theory. Endorsing the value of critical hermeneutics in social sciences, Bleicher (1982) argued that it would be shortsighted to preserve the subject-object stance. He claimed that persisting with 'objectivist remnants' would facilitate epistemological error leading to political misinterpretation of dialogue, distortion of the subject matter and ultimately, it would negate a hermeneutically sensitive approach to understanding.

The point Kögler (1999) made is that critical hermeneutics can be attentive to both terms of its methodology. It is a critical methodology because it questions the values and ideologies that underpin knowledge and social practices; it is an interpretive (hermeneutic) methodology because it claims that in qualitative research there is only interpretation, no matter how vigorously some researchers may argue that the 'facts' speak for themselves. The implied contradiction may be resolved if one acknowledges that human existence is always already meaningfully (hermeneutically) experienced. Moreover, even the 'facts' of life need to be articulated (the human science text) and this is inevitably an interpretive process (van Manen, 1990). By means of a more reflexive approach to interpretive practice, Kögler (1999) sought to reveal the underlying structure of the social world for analysis. In an attempt to systematically explicate the concept of critical interpretation, he linked Foucault's discourse analysis with Gadamer's hermeneutic ontology in relation to the "nature of preunderstanding and the dialogic nature of interpretation" (Kögler, 1999, p. 2).

Preunderstanding and dialogue

Critical interpretation in research requires the dialogic process to focus on the circumstances through which meaning is constructed (Kögler, 1999). In this way, the things which unconsciously shape understanding or the *worldview* are revealed and made visible. Initially, Kögler (1999) focused on developing a methodology to facilitate analysis of the influence of power practices on preunderstanding. Building on Gadamer's notion that "understanding is not possible without preunderstanding" (p. 19), Kögler argued that within the linguistically disclosed preunderstanding there is a need to distinguish conceptually (and ultimately methodologically) different symbolic orders, social power practices, and individual meaning perspectives. In this way the interpreter can bring forth in a thematically open manner the basic assumptions that intrinsically determine understanding.

Kögler (1999) was encouraged by Gadamer's argument that preunderstanding and dialogue were significant components of the "hermeneutic event" (p. 20). Kögler believed this stance enabled a constructive analysis of the interpretive act because the background of interpretation and the orientation of the interpreter were recognized and thus could be thematised. Through dialogue, understandings and preunderstandings are revealed along with the historical, social, and cultural influences which shaped those understandings and the practices they invoke. This builds on Gadamer's theory that "every act of understanding discloses another's meaning against a shared historical background that binds text and interpreter together" (Kögler, 1999, p. 25). This theory is endorsed by Kincheloe and McLaren (2000) who stated that "critical hermeneutics builds bridges between reader and text, text and its producer, historical/cultural content, and one particular social event and another" (p. 286). In other words, listening and relating to the voices of research participants who live with dementia opens up the critical research process to the problems they have to deal with on a daily basis as a result of issues of power, justice, and democracy.

Influenced by Gadamer's notion of understanding as subject to an historical/cultural preunderstanding, Kögler (1999) wondered how the necessity of drawing on previous knowledge can be reconciled with the goal of interpretive understanding. If preunderstanding makes possible understanding and as Kögler professed "it is impossible to 'get behind' preunderstanding" (p. 83), then understanding another's meaning and the

truth of interpretation is transient. According to Gadamer, this knowledge, which is made known through linguistic disclosure, is always to some extent beyond the control of the subject. Kögler claimed that this stance underpinned Gadamer's theory, which implied that interpretive understanding is beyond subjective control and is in effect a "transsubjective" event of dialogue" (p. 13). In other words, Gadamer argued that any dialogic achievement goes beyond, and ultimately undermines, the methodologically trained interpreter. In response, Kögler challenged Gadamer's stance, claiming he overemphasized the transsubjectivity of hermeneutic interpretation when he inferred that "subjective reflection is necessarily subordinate to historical tradition" (p. 34).

In disagreeing with Gadamer's notion of the interpretive process as an unrecoverable event, Kögler (1999) held it contrary to the tradition of philosophical hermeneutics itself. The foundation of the hermeneutic model is based on the interplay between interpreter and tradition, in that the individual interpretation of tradition is what keeps tradition alive; one sustains the other. As to which is more important, Kögler proposed that Gadamer sought to answer with his linguistic ontology in favour of tradition, in terms of his notion of understanding as an event. Kögler also disputed Gadamer's argument, which posited the transsubjectivity of the hermeneutic process. He did not accept that interpretive understanding is necessarily subject to preunderstanding. Rather Kögler contended that ever new and meaningful aspects of the subject matter may be discovered over time, making a definitive understanding impossible. Further, he suggested that the phenomenological analysis of understanding, which brought out the nature of understanding with reference to a linguistically mediated preunderstanding, ultimately directed the argument towards the hermeneutic significance of language and of conversation. According to Kögler (1999) this basically indicated that, "interpretive understanding is a linguistic and linguistically determined process" (p. 37). Considered in relation to a social inquiry such as this, if people preunderstand themselves through linguistically arranged consciousness, then researchers must treat these preunderstandings, and their own, as necessary parts of the whole. That is to say, if the participants accept as true the socially constructed beliefs about dementia then the information they share will be influenced by this.

Subjective nature of interpretation

Taken as an event, Gadamer's ontology of language transcended individual consciousness and opened the way for a transsubjective process of understanding. Indeed, from a Gadamerian stance, language and the world come together to create, and be created by, language. In other words, people survive in the world only insofar as they speak a language, and through speaking the language they can relate to others. For example, Gadamer (cited in Kögler, 1999) claimed "whoever speaks a language that no one else understands does not speak. To speak means to speak to someone" (p. 42). In this way dialogue, as the typical form of human linguistics, can be found at the heart of a hermeneutic ontology of language.

Kögler (1999) questioned the dialogic nature of language proposed by Gadamer in the belief that it restricted an open understanding of meaning. Rather, Kögler focused more on how dialogic communication could be used as a mechanism for coordinating action towards a common goal. He consequently turned to Habermas who suggested the linguistically constituted preunderstanding of social agents is dependent on symbolic factors which foster communication between two people who have enough in common to generate meaning and knowledge. Kögler strongly defended the notion of philosophical hermeneutics whereby dialogue is the communicative form of linguistic understanding. Therein every conversation between two people is considered to be fully dependent on, and only achieved through, specific symbolic cultural preconditions. Kögler argued that preunderstanding involved linguistically constituted and expressive knowledge that increases awareness and can be altered with experience. He claimed experience allows us to see things differently and thus our perspective is altered in ways we never intended or anticipated. Inasmuch as belief guides awareness, though sometimes disillusioned by experience, unwanted awareness is still a source of conscious experience. In moving on from adverse negativity, knowledge can, through encountering change, alter itself. From this perspective, Kögler argued that when two people in conversation share disparate views on a subject, precisely insofar as one discloses their preunderstandings to the other, the other perceives his or her own view differently. Thus a dialogic movement is set in motion which the communicators are unable to direct or control. In other words, learning from people with dementia is bound to influence understanding of the difficulties encountered in doing everyday occupations when living with dementia.

Language of interpretation

Philosophically, this discussion has relevance to Gadamer's claim that understanding is an event. According to Kögler, (1999) the universality of the claim can be justified "only if dialogic understanding is viewed as a transsubjective event behind which the interpretive theorist is incapable of going" (p. 56). The critique Habermas brings to bear on the relationship between hermeneutics and social power also has significance to this discussion. Habermas critically assessed the existential-ontological turn of hermeneutics whereby all conscious reflexivity was grounded in tradition-rich, but ordinary language. For Habermas, the claim that we are incapable of rising above the use of simple language reduces history to cultural tradition, because in this way the common meaning is viewed entirely from the vision of the social actors. This debate involves the farsighted theory that linguistic awareness establishes the material being of life's traditions. In contrast, to adequately grasp the ways in which linguistic relationships are formed through power and labour, it is necessary to draw on an "objective reference system" (Kögler, 1999, p. 73). According to Habermas, this system would enable the interpreter to thematise how objective power structures could be overcome through the "world disclosing capacity of language" (Kögler, 1999, p. 73). Habermas argued that the tradition-oriented preunderstanding of hermeneutic understanding must be replaced by a preunderstanding systematically related to language in general. Thus for Habermas, an exploration of the social power practices which disable people with dementia can best be achieved in an analysis of the language of discourse.

Language of discourse

In contrast to Habermas, Gadamer considered the original function of language with respect to power relations. He emphasized language's ability to critique and highlighted the relevance of language for the reality of the world. He opposed Habermas's conception of an objective reference system unless it was within a historical, culturally localized framework of language. Thus according to Gadamer, an analysis of power practices is only an interpretation of these conditions, and in this way language is the all-inclusive medium of meaning. Kögler (1999) posited Gadamer's response to Habermas as seeking to shape a critical analysis that reflected the aim of thematising social power. By introducing the pursuit of common language as a precondition for critical consciousness, Gadamer placed

critique within our informal use of language as opposed to a distinctly theoretical orientation. He perceived critique to be a genuinely inherent feature of language.

The fact that we move in a linguistic world and grow into our world through linguistically performed experiences, does not deprive us of the potential for critique. Quite the contrary ... Indeed we owe our aptitude for critique to the linguistic capacity of our reason; and we are not in any way obstructed from our reason by language. (Kögler, 1999, p. 75)

Therefore according to Gadamer, the linguistic preunderstanding of tradition is certainly adequate enough for a critical analysis of power relations. For Gadamer, normal everyday language provides us with the ability to relate both reflectively and critically to social power structures and theories of ideology.

Theory of ideology

At the time of the debate, Habermas objected that the medium of science itself is changed through reflection and more precisely that this knowledge has been handed down by the idealism of the philosophical hermeneutic tradition (Gadamer, 1976). Habermas characterized ideology as a distorted form of communication, and thus an obstacle to understanding. Indeed he advocated that as a form of false consciousness, ideology preserves the legitimacy of existing power structures by concealing their capacity for oppression. He argued that through the use of ordinary language, ideological power hides contradictions in the social system and in this way ensures the continuing domination of certain groups within society (Fairfield, 2002). In showing how social practices are energized by language, work, and action, Habermas proposed hermeneutical reflection must pass into criticism of ideology. The practical intent of his critique of ideology was to provide a scientific framework from which to critique societal discourses and traditions with a view towards enabling the emancipation of people, such as those with dementia who are disadvantaged by social power structures. Gadamer countered that Habermas's notion of self-reflection represented a thorough misunderstanding of the way in which social phenomena are understood. Kögler (1999) contended that Gadamer's objection to the ideology-critical position remains valid because Habermas failed to reconcile the need for a critique of existing practices with recognition of the limits of human understanding.

Concepts of meaning

According to Kögler (1999), unraveling the taken-for-granted ideological systems embedded in sociocultural symbols of meaning and the typically invisible ways in which the meanings are incorporated into daily life is complicated. To avoid the limitations of Habermas's ideological-critical view and Gadamer's linguistic ontological grounding of understanding, Kögler proposed that a hermeneutic theory of preunderstanding needed to be adapted and developed. Accordingly, Kögler reflected on the hermeneutic confidence which imagined itself capable of insight superior to historically situated knowledge. He emphasized critical analysis of the function of social power structures by taking into consideration the holistic hermeneutically-informed preunderstanding of the interpreter.

Kögler (1999) wanted to show how hermeneutic presuppositions restrict the interpretive consciousness, thus explaining how “symbolic orders, social power, and the individual's understanding of self and being, hang together as features of preunderstanding” (p. 85). He credited Gadamer's philosophical hermeneutics with opening up the possibility of viewing dialogue methodologically, reciprocally and critically. He presented a theory of dialogic intersubjectivity within which alternative views allow a differentiation of, and a getting behind, preunderstanding using the concepts of dialogic understanding, preunderstanding, and linguistically determined understanding. Further, he considered the breaking down of preunderstanding essential, not only to reveal how power practices influence understanding, but also to support his own division of preunderstanding “into symbolic orders, power practices and individual perspectives” (p. 87).

The structure of understanding

In order to make his position conceptually plausible, Kögler (1999) differentiated between the features of preunderstanding using Heidegger's three-faceted explanation of the ontological background of understanding. This notion of the ‘fore-structure of understanding’ encompassed the components of fore-having (social action context), fore-sight (interpreter's context), and fore-conception (determinate way of imagining). Taken together these three features form the ontological preunderstanding, that is, “our projection of being that is already brought into every thematic interpretation” (Kögler, 1999, p. 89). In using these domains to revoke Gadamer's “all encompassing linguistic ontological conception of understanding”, Kögler (1999, p. 89) claimed that these features “constitute

aspects of the being of Dasein” (identified ontologically as understanding) as they provide a backdrop that cannot be dismissed from unambiguous interpretation. Further, “they determine the explicit meaning to be grasped in interpretation precisely through the prior constitution of meaning” (Kögler, 1999, p. 89).

Based on the assumption that prelinguistic practices are sufficient for symbolic meaning-constitution, the process of meaning-constitution is unreservedly given over to language as the most fundamental dimension of being. Kögler (1999) alleged there are difficulties related to this stance, specifically the reduction of different symbolic orders, the permanent anonymity of the influence of social power relations on the subject’s hermeneutic understanding of self and being, and the denial of individual meaning perspectives within the linguistic experience of meaning. In seeking to understand the features of preunderstanding, Kögler (1999) suggested these ontological reductions could be avoided through an analysis of fore-structure as the “background of a linguistically mediated and linguistically achieved dialogue” (p. 91). Kögler (1999) considered Heidegger’s theory of fore-structure a good foundation for the dialogically understood process of interpretation. His goal was to reframe the theory without falling into the insoluble impasse of the hermeneutics of Dasein and practical holism, and “without needing to succumb to the misguided idealism of linguistic ontology” (p. 92).

Power practices

Having linked the model of dialogue to a Heideggerian analysis of fore-structure, Kögler (1999) went on to consider the ways in which social power practices shape our interpretation of self and other. He outlined three steps that he deemed necessary to achieve this. Initially, he considered “explicit linguistic understanding of something as something” (p. 93) and explored the ways in which it is essentially based on innate background assumptions (fore-conception). He then addressed the extent to which power practices filter through to influence symbolic disclosures (fore-having). Finally, Kögler questioned the influence of power practices, and their outcomes, on the interpreter’s individual perception of meaning (fore-sight). These three steps also informed this research process inasmuch as they opened up a means to show how knowledge and understanding of dementia is shaped. Coming to see (dementia) *that which is* the ‘thing in itself’ as disclosed in dialogue, recognizing the shaping of (reality) *that which is* through social practices, and investigating

the relationships between power, oppression, and the ways in which reality is perceived (by others) *that which is*, opened the way for a deeper analysis of the influences which shape the daily life of people with dementia.

Episteme and discourse

In order to specify how the influence of “power on preunderstanding can be grasped conceptually and thematised critically”, Kögler (1999, p. 93) turned to Foucault’s conceptualization of public discourse and knowledge. Kögler considered Foucault’s model of symbolic order with its concepts of episteme and discourse an insightful means of examining social power structures and dialogic praxis. According to Kögler (1999), “no one has so radically broken with the discourse-extrinsic conception of meaning as the early Foucault” (p. 94).

Retracing Foucault’s footsteps, Kögler (1999) reframed the theory of fore-conception as an ‘episteme’. Defined as ‘an order’, episteme is “at one and the same time, that which is given in things as their inner law, the hidden network...which has no existence except in the grid created by a glance, an examination, a language” (p. 95). Kögler presented discourse as that which “determines the horizon and background for the experience of objects, subjective speaker roles, the conceptual field, and the thematic options” (p. 96). For Foucault, discursive praxis is subject to its own rules, “rules which determine what will be an object of research, who may speak and in what way, what will qualify as scientific terminology, which questions and problems will be discussed and researched” (p. 96). This statement has relevance here since in the past it was assumed that people with dementia were unable to engage in dialogue about their experience and so they were not considered capable of taking part in research.

Kögler’s hermeneutic reconceptualisation of Foucault’s methods makes it possible to explore how the experience, fears, and deprivation of living with dementia are shaped by social structures and practices. Foucault advocated that power is essentially determined and made effective through the power laden-ness of social practices. Furthermore he stated:

What makes power hold good, what makes it accepted, is simply the fact that it doesn’t only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. (Kögler, 1999, p. 99)

By showing how power practices function “within the symbolic order of discourses and dialogues”, Kögler (1999) ultimately wanted to explore and reveal how interpreters relate to “this implicitly determining complex of ontological premises and social power practices” (p. 94). Whilst interpreting Foucault’s episteme as a system of meaning that obeys internal rules, Kögler argued that Foucault failed to see that meaning can be retained as part of every discourse, and used to deflect the power of intuitive subjectivity. Foucault’s theory of discourse, particularly in relation to the features and rules of a specified discursive praxis, was too narrow for Kögler. He proposed discourse theory as a tension between the pervasive understanding of self and being, and actual social power relations.

Interpretation of power practices requires language that can grasp the insidiousness of reality making dimensions of control (Kögler (1999)). This insight into discourse analysis and social power practices is central to the formulation of Kögler’s critical interpretation. In essence, Kögler alleged that open dialogue enables the interpreter to avoid preset limitations on discourse. Specifically, because the concept of episteme was introduced as “the ontological level of fore-conception of dialogic speakers, the abstract sublation of subjects within the event of language (Gadamer) as well as their concrete confinement within discursive orders (Foucault) are overcome” (Kögler, 1999, p. 97). By distinguishing conceptual differences between symbolic orders of discourse, social power practices and individual meaning perspectives, Kögler cleared the way for a hermeneutically sensitive analysis of the influence of power practices that shape understanding of dementia.

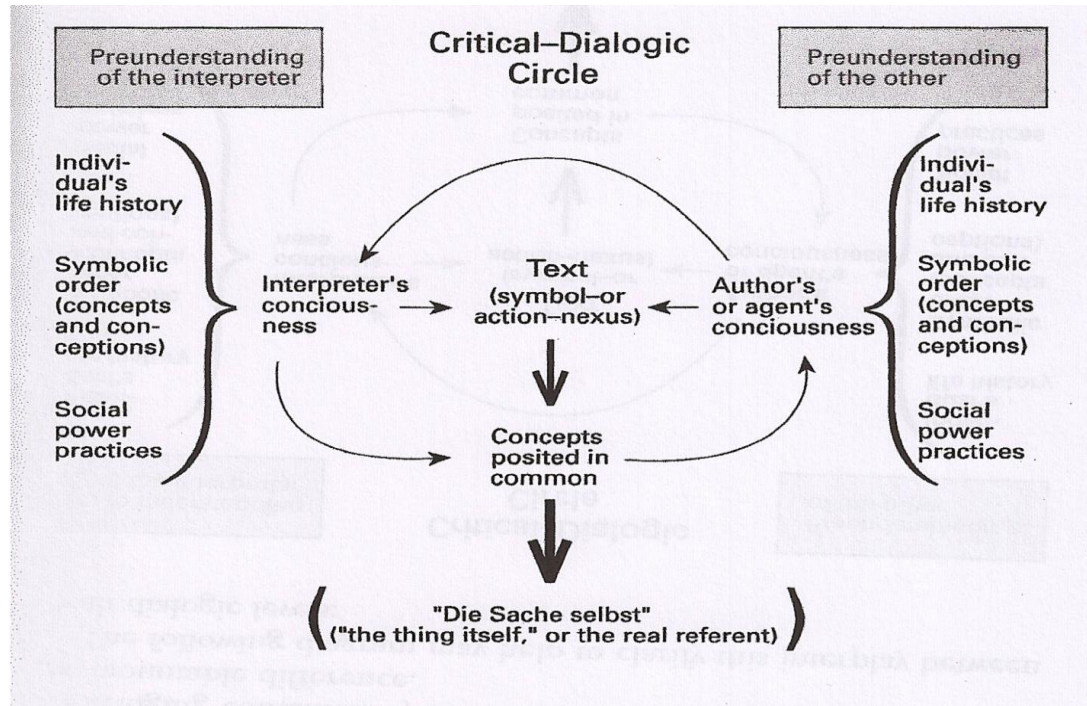
Hermeneutic circle

According to Kögler (1999), the central aspect of the hermeneutic circle acknowledges that exposure to the ways in which other people connect their everyday experiences to a socially symbolic representation of those experiences, enables the researcher to gain distance from personal assumptions. Such a radical self-reflection involves unraveling the ideological systems ingrained in such representations. Clarifying the taken-for-granted meanings upheld by social symbols and the typically undetected ways these meanings are circulated in everyday life is complicated. Nonetheless, by doing this it becomes possible to see ourselves “as other from the genuinely understood perspective of another” (Kögler, p. 172). To disclose meaning productively, Kögler (1999) advocated that the interpreter “must

prepare in a very specific way” (p. 21). In essence, s/he must be free of a bias towards meaning.

The following diagram depicts the relationship between the two levels of discourse:

Figure 3 The hermeneutic circle



(From *The Power of Dialogue* (p. 171), by H. H. Kögler, 1999, Cambridge, Massachusetts: MIT Press. Copyright (1999) by the MIT Press. Reprinted with permission.

Habermas and Gadamer’s position remains crucially important here because there is merit in their insistence that the interpreter relies on preunderstanding which is essentially deemed to be ‘truth’, and their inference that content-related understanding requires the dimension of validity (Kögler, 1999). Conversely, Kögler argued that understanding necessarily begins within the horizon of the interpreter before expanding into a substantially different premise that is equally meaningful and credible. An interpreter cannot fully understand the experiences of people with dementia by proceeding from a personal interpretation of reality because “meaning depends on a holistic background that is structured along complex symbolic, practical, and subjective lines” (Kögler, 1999, p. 168).

Symbolic orders

Symbolic orders are defined by Kögler (1999) as power structures that operate to dominate and shape consciousness. They are implicit in every explicit understanding (Kögler, 1999). In other words, meaning is grounded in discourse, the central rules of which include a set of social rules that are legitimised as natural and inevitable. Discourses on dementia assume that when people are diagnosed they will follow a specific downward spiral of cognitive decline and behave in certain ways. Kögler (1999) argued that to understand a symbolic order it is necessary to “grasp the regulative function of basic assumptions that give statements, perception, and actions their meaning within a particular context” (p. 180). In other words, to understand the social construction of dementia it is necessary to grasp the source of specific beliefs, how they came into being, and how they might influence actions towards a person with dementia.

To add weight to his argument, Kögler (1999) turned to Foucault’s theories on the ‘archeology’ of discursive formations and the ‘genealogy’ of power practices. Where the archeological analysis reveals symbolic structures, the genealogical investigation addresses individual and social techniques of “normalisation, control, and exploitation” (p. 175). Kögler argued that the insights found in Foucault’s early work could be made productive through integration with a dialogic hermeneutics that proceeds from one’s own preunderstanding. He proposed a critical discourse analysis that accepts preunderstanding as a component of interpretive understanding.

Kögler (1999) advocated that preunderstanding can be channeled into a particular interpretive effort so that the underlying symbolic order is revealed. He argued that to understand the symbolic order of others it is necessary to come to terms with the ways in which symbolic concepts come into being. Whereas interpretation starts with mutual ideas on certain notions, increased understanding of what specific concepts mean to others enables the interpreter to distance him/herself from personal understanding so that the other’s meaning can be grasped. In this way critical hermeneutics does not attempt to change difference through interpretation, rather it seeks to take up the disparity and use it effectively towards a new understanding (Kögler, 1999). Thus enhanced knowledge provides the basis “for an analysis of power structures within our conceptual understanding of reality” (Kögler, 1999, p. 213). Many conceptual issues arise as a result of living with

dementia, for instance, how people with dementia are perceived, referred to, and treated will ultimately affect their behaviour.

Critical theory of power

Critical theory was previously concerned with the need to understand the various and complex ways that power operates to dominate and shape consciousness (Kögler, 1999). Kögler advised that before undertaking any critical analysis a researcher must be aware of the intrinsic connection between power dynamics, freedom, and domination. In effect, he argued on the basis of Foucault's later work that power can only be exercised over people who are free. People who are not free are dominated.

To advance his theory of critical hermeneutics Kögler (1999) presented what he hoped would be a plausible hermeneutic analysis and critique of power, integrating a reinterpretation of Foucault's analytic of power whereby archeology was extended through genealogy. Negotiating a link between the early, middle, and late Foucault, Kögler differentiated between power, freedom, and domination to create a space in which "a hermeneutic critique of power situates itself with respect to social contexts" (p. 235). At this point, the concept of resistance was introduced. According to Kögler (1999), power practices that lead to dominance and the struggle for freedom from such practices come together in the context of resistance. In order to identify the forces and constraints that shape people's potential life actualization, power must be understood in terms of the way it shapes a person's self-understanding. In other words, people suffer under given conditions in relation to their hopes and ambitions in life.

Kögler (1999) argued that the hermeneutic form of critique does not rely solely on judging and analyzing power but on "understanding another linguistic being" and recognizing that the other being is "ontologically equal" (p. 108). This theory acknowledges the multiple realities of people in society and recognizes that each reality is different and equally important to understanding. Thus, Kögler (1999) advocated that by using an "archaeology of their self-understandings and a genealogy of the related power practices" to reveal socioculturally implanted symbolic orders, it becomes possible to give people "a space for reflection and action over against established interpretations and structures of domination" (p. 239). Accordingly, people who want to resist power practices must first define and

clarify their identity in a symbolic as well as a material sense. Only when people determine their own way of being in the world can critical hermeneutics dispel power-laden forms of identity, and open up possibilities for self-empowerment (Kögler, 1999). This notion is endorsed by Kincheloe and McLaren (2000) who stated, an important facet of critical research addresses the dynamic aspects of power and “its ability to empower, to establish a critical democracy to engage marginalized people in the rethinking of their sociopolitical role” (p. 283).

From critical theory to critical hermeneutics

In its critical theory-driven context, the purpose of hermeneutic analysis is to develop a form of criticism revealing power within social and cultural contexts. To this end Kögler (1999) argued that the critical hermeneutic task is to identify “the conceptual and methodological space in which an interpretive practice of critical self-reflection can be most completely and productively achieved” (p. 254). Accepting that no interpretation is faultless, because all researchers are bound by the theories and perspectives of the world in which they live, Kögler (1999) advised that the purpose of a critical interpretation is to analyze and reveal the effect of existing social and symbolic orders on people who are deprived and marginalized. The following pages will explain how the philosophy of critical hermeneutics is located within the action methodology.

Action research methodology

Typically, qualitative research seeks to explore and interpret the experience of others, but it seems both naive and audacious to presume that one can fully understand the life of another when one has not lived with the same experience. Action research is a form of qualitative inquiry that posits a collaborative, action-based process to address common needs arising in daily life. In contrast to traditional research methods which use a variety of theoretical frameworks to generate knowledge to reproduce as closely as possible the reality to be interpreted (Fals-Borda & Rahman, 1991), action research is undertaken in this study to generate knowledge that points to a course of action. Understanding is enhanced by critically analyzing assumptions underlying knowledge derived from historically-shaped and politically-driven traditions (Williams, 1999).

The early history of action research is grounded in social theory and critical social science (McTaggart, 1994), and “in reality demonstrates the convergence of several distinguished

intellectual traditions” (McTaggart, 1997, p. 26). Since its inception, several models and descriptions of action research have been advanced in literature with terms such as collaborative research (Heron, 1996), participatory research, and participatory action research (Fals-Borda, 2001). These days the term *action research* is used for a range of research activities which may be better described as ‘applied research’ because they do not always require participation. From McTaggart’s (1994) perspective, this is action research from the point of view that the research informs the action.

Action research shares its purposive elements with critical theory, although the various practices of action research are informed by a range of paradigms and epistemologies. In academic literature, action research is variously described as evolving from the work of John Dewey (throughout his career), Jacob Moreno in the 1920s, John Collier in the 1930s, and Kurt Lewin in the 1940s (McNiff & Whitehead, 2006; McTaggart, 1994; Reason, 1994). During the 1970s Habermas (1973) rejected the idea of action research from a theoretical perspective. He alleged: “the normative basis for a social theory constructed with practical intent” (p. 16) is dialectically illogical. On the contrary, Dewey was eloquent in his criticism of the traditional separation of knowledge and action. During his long career he argued for a ‘theory of knowledge’ that would be a paradigm for both scientific method and social practice (Adelman, 1993). Lewin demonstrated the integration of science and practice through group dynamics and action research and it is for this reason that I look at his work more closely.

Kurt Lewin

Lewin is commonly credited with first use of the term ‘action research’ (Adelman, 1993; Gustavsen, 2008; Hart & Bond, 1995). Universally recognized as a modern pioneer of social psychology, Lewin was interested in the scientific study of people in society. In his search for a deeper insight into the laws which govern social life, Lewin’s scientific interests focused on the problems of organisational development and group dynamics. He described action research as “a comparative research on the conditions and effects of various forms of social action and research leading to social action” (Lewin, 1948, p. 202). Lewin’s analysis of the nature and causes of social conflict and his search for techniques capable of resolving them were a recurrent theme in his work. In trying to build a bridge between theory and reality, he laid out the framework for action research when he

described “a spiral of steps, each of which is composed of a circle of planning, action and fact-finding about the result of the action” (Lewin, 1948, p. 206). Lewin believed that for change to take place in any given situation, the total situation had to be known. If isolated facts were used, the picture would not be complete.

Lewin (1948) argued that creating an empirically verifiable theory was the essence of science. He advocated that research should be carried out in real life situations, with a focus on the underprivileged group or fighting prejudice “to seek the wisest solutions and best practicable administrative alternatives” (Lewin cited in Adelman, 1993, p. 8). He described a “constant intense tension” (Lewin, 1948, p. xvi) between research and theory, because the many influences underlying an issue, and knowledge of the neglected group in question, had to be considered. Lewin theorized that encouraging self respect in disadvantaged groups was the solution to many social problems. His original ideas have remained influential as has the cycle of action steps: observe – reflect – act – evaluate – modify. The Lewinian spiral metaphor reflects the real possibility of people acting differently as a result of progressively learning from experience. In the 1950s action research was taken up by educators, specifically the teaching profession and is now widely accepted as a form of professional learning across many professions (McNiff & Whitehead, 2006).

Learning through action research

There is significant variance in the use of the term action research in the literature (Bate, 2000). Described as a “family of approaches” (Reason & Bradbury, 2006, p. xxii) action research is not only a procedure of exploration and intervention, it is also a process for change (McNiff & Whitehead, 2006). Whereas Carr and Kemmis stated in 1986 “there are two essential aims of action research: to improve and to involve” (p. 165), more recent literature claimed that action research is a means of generating knowledge to inform action (Gustavsen, 2008; Kemmis, 2001). So it would seem that the range and perspectives of action research have undergone a developmental process. Reason and Bradbury (2006) confirmed this when they stated “there can never be one ‘right way’ of doing action research” (p. xxiii). For some researchers, action research addresses questions of a personal nature, while others use it as a way to develop knowledge that can be used to improve organizations (Reason & Bradbury, 2006). A smaller body of action research which

Kemmis (2001) labeled critical or emancipatory action research is used to create change on a large and/or small scale and/or influence policy decisions.

Critical action research is primarily designed by a researcher who is interested in identifying and solving the problems of a specific group (Soltis-Jarret, 1997). This report is supported by McNiff and Whitehead (2006) who argued that action research developed out of critical theory and then went beyond. Where critical social theory aimed only to understand a given situation, action research went into action to address the question “How can it be changed?” (McNiff & Whitehead, 2006, p. 41). According to Kemmis (2001) this form of action research seeks not only to improve outcomes while improving people’s self-understanding, but it also assists people to arrive at a critique of their social environment.

More recently Kemmis (2010b) argued that action researchers should focus on the ‘happening-ness’ of action and practice, rather than on how research augments our understandings. He posits that action research has an obligation to generate knowledge/action that allows people to live well. Furthermore, he suggested that in current conditions this means not only changing the ways in which we relate to each other, but also pursuing a shared goal of changing practices so that we can live sustainably. Thus he explored the place of action research in shaping and making history by changing what is done. Based on philosophical underpinnings, Kemmis (2010a) stated that action research needs to change history to make the world a better place for a specific group. Moreover, he hypothesized that “the search for evidence, for clearer and deeper understanding of the consequences of what we do – is the research part of critical action research” (Kemmis, 2009, p. 473). This type of action research aims to intervene in the social, practical, and historical processes of daily life with a view to reconstructing the social environment (Kemmis, 2010a). Breaking free from regular routines and habits to seek a new way of being is at the heart of critical action research (Drummond & Themessi-Huber, 2007).

Action researchers generally design their projects in two ways that are comparable to qualitative designs. In the first instance they are field-based, and secondly, they are usually longitudinal and engaged (Reason & Bradbury, 2006). Qualitative methods such as interviewing, focus groups, social network data gathering, observation, and field notes are used and combined, as required for the aims of the study (McNiff & Whitehead, 2006). A

unique feature of action research is the fluidity of the cyclical process which is grounded in creative action rather than a series of well-defined steps (Drummond & Themessi-Huber, 2007). Given the opportunistic, exploratory and emergent nature of most action research, the action-reflection process does not necessarily follow a specific order (Bate, 2000). Rather the cyclical process depends on how best to accomplish practical and other outcomes deemed essential by those involved in research. According to Lewin (1948), any attempt to change or improve a specific situation has to face a wide variety of tasks and includes dealing with problems of attitude, social stigma, leadership, status and culture, in many aspects of community life. Although the process of action research is unpredictable the unifying theme is unmistakable. The specific group to which a person belongs is the ground for his perceptions, feelings and actions (Lewin, 1948).

According to Reason (1998), critical action research has the potential to reveal and interpret discrimination in social experience, and more importantly to influence a process of change. It is frequently used to plan and enact solutions to community problems or service dilemmas, and in doing so shares its purposive elements with critical theory. The researcher, as a facilitator, takes on an extremely important social and political position (Soltis-Jarrett, 1997) as s/he guides the research group using tenets from a critical perspective.

The many models and descriptions of action research recently advanced in literature have drawn on long-established traditions that put participation, action, and adult education at the centre of attempts to liberate marginalized people. Although opinions differ among authors, there is a general consensus of opinion about flexibility in the methodology (Fals-Borda, 2001; McTaggart, 1997; Park, 1993; Reason, & Bradbury, 2006; Williams, 1999). That is, given the diversity of fields from which action research has, and continues, to evolve as a way of improving or informing social practices, it is quite understandable that no one project will faithfully follow a process of steps (Park, 1993). Social situations are often complex, and it is not possible to anticipate all that may need to be addressed. Thus action and reflection allow for changes in plans for action as participant understanding develops incrementally (McTaggart, 1997). This concept of action and reflection is closely aligned to critical hermeneutics as, according to Kögler (1999), “it is this type of situated,

yet not power blind form of reflexivity on which critical hermeneutics bases both its methodology and its ethical hope” (p. 275).

Summary

This chapter outlined the relationship between critical hermeneutics as depicted by Kögler (1999) and critical theory before moving on to show evidence of a link between the philosophical base and the methodology. The use of critical hermeneutics will facilitate the thinking process and clarify, for the purpose of critical interpretation, the conditions under which understanding can take place.

The research question “How can people who live with dementia in the community be supported to engage in daily activities?” required a qualitative methodology that would explore the participants’ experience and influence learning. Action research resonates with both the philosophy of critical hermeneutics and the purpose of this study. The selection of an action approach was based on the premise that people with dementia represent a population of people who have traditionally been disadvantaged and excluded from research. Thus, a component of the action in this study will describe the way in which the research challenged me as the researcher to find an effective and meaningful way of including them in the research process.

In contrast to a search for ‘truth’, the ultimate goal of this study is to “open communicative spaces in which the ‘way things are’ is open to question and exploration” (Kemmis, 2008). In that context, interpretive truth required a collaborative process with participants. To that end the methods needed to be flexible enough to capture the reality, to have participants discuss potential interventions in action, reflect on the outcomes, and to provide opportunities for the researcher and the participants to come together as a group to consider courses of action. The following chapter documents that process.

Chapter Four

Research Design and Conduct

“No action without research and no research without action”

Kurt Lewin (1890-1947)

Lewin argued that action research is a legitimate means of closing the gap between theory and practice (cited in Adelman, 1997). Designed to help drive change, in a society with little understanding of what it means to live with dementia, the theory behind this action research study is that health professionals and thereby, society, can learn from people whose life is shaped by dementia. The knowledge generated can then be put into action to inform practices that will make a difference for their good. At the outset, there were no preconceived ideas of what these practices might be or whose practices might be informed. Rather, there was a general expectation that the use of occupational therapy knowledge would be constructive.

Whereas the philosophical and methodological underpinnings presented in the previous chapter provide a conceptual basis for critical understanding, in any research project seeking evidence to bring about change the methods are of key importance. Therefore this chapter will outline the research design and methods used to bring inquiry and action together in this study. As discussed in the previous chapter, the methods are informed by Kögler’s (1999) version of critical hermeneutics, which aims to create a conceptual and methodological space in which a process of critical interpretation can be completely and effectively achieved. The methods used in action research are flexible, but a rigorous and demanding approach to knowledge is advocated (McNiff & Whitehead, 2006; Reason & Bradbury, 2006; Winter & Munn-Giddings, 2001). Thus, the explanation which follows will reveal how the data were gathered, analyzed, and informed by critical hermeneutics, to identify the action required to support people in the early stages of dementia to engage in daily activities in community settings.

An exploration of the reality of living and working with the unpredictable, progressive nature of dementia requires more innovative and flexible methods than the scientific methods previously used by medical researchers seeking to understand the etiology and

progression of this health condition (Chenoweth & Kilstoff, 1998). Much of the thinking done by scientific researchers is theoretical rather than practical. It does not help people to work out how to change things that are wrong in their lives (Heron & Reason, 2001). Of significance was my belief that power injustices prevail in relationships between people with dementia and wider society. An action approach enabled practical exploration of these relationships and how discourses and actions might change. In the beginning, the design was driven by my conviction that people with dementia should be included in, and should inform, research seeking to produce knowledge that would enable them to engage more fully in daily activities. Capturing their worldview from a critical hermeneutic perspective would not only make sure their voices are heard, but would also inform and shape understanding and actions.

A brief outline of the research process

As outlined in Chapter 3, action research is a process of actions that can change people's practices and the conditions under which they practice (Kemmis, 2010a). The informed actions undertaken in this study did not occur all at once rather three stages of data collection and analysis informed the action which then followed. The initial actions came after I urged participants to be proactive in their daily activities. Feedback from the first focus group provided another source of data collection which was used to inform a second round of action at societal level. Further feedback from the second focus group informed a third round of action at national level.

Engaging with and listening to participants, before writing, is the method through which knowledge is gained during the dialogic process of interviewing. This allows the researcher to grasp the participants' personal experience, and preunderstandings. This phase involves the gathering, transcribing reading, and coding data before creating initial categories and themes. According to Gadamer (1976), it is necessary to be able to relate to the background and context of the participants in order to appreciate the influences that contribute to their understanding. Thus the guiding principles which shape understanding in this study include:

- Gathering information from participants who shared the common problem of how to live with dementia;
- Reflecting on the data to reach a basic understanding;

- Collaborating with participants to interpret experiences and make decisions;
- Identifying and viewing the way things are socially constructed; and
- Validating findings through a rigorous justification process.

Equally important, to provide a link between the unique experience of dementia and the socially constructed understanding of living with dementia, research requires a person-centred approach (Kitwood, 1993b). This insight is important because social services are designed for groups in society but in the end, they must deal with individuals and their family/whānau. Consequently, I decided there was no requirement for all the participants to come together in order to take part in this study. I acknowledge however, that knowledge, including scientifically derived knowledge, is socially constructed and must be understood in a group context (Kögler, 1999).

Data collection and analysis initially focused on gathering and interpreting data in a small group context (the person with dementia, a family/whānau member and me, the researcher). This involved understanding each couple's experiences, challenges and successes, and produced the first layer of action when feedback generated at that level directly influenced the participants' experience. The process was then expanded for the next layer of collection and analysis through focus group discussions to confirm my understandings and get participant feedback on my proposed actions at a broader social level. For instance:

- Conference presentations that challenged the knowledge and prevailing attitudes and practices of health and disability service providers;
- Participation in the review of Government policy directions; and
- Facilitation of a seminar and workshop intended to inform and educate front line service delivery with a view towards encouraging change in society.

The goal of the seminar was to bring together people with dementia, caregivers, and service providers, to identify and acquire skills that would help to create meaningful, engaged lives for people living with dementia in the community. The workshop was designed to bring together interested parties to explore the feasibility of establishing a centre to promote excellence in dementia care in New Zealand through research, education, and training.

My affinity with the participants was based in my experience of caring for Ana, my work with people with dementia, and my desire to understand better how people with dementia might be assisted to live a balanced lifestyle that supports well-being. Without further preamble this chapter will outline the methods and methodology used to establish the validity and credibility of this action research, but first, the process of gaining ethical approval will be presented.

Ethical considerations

I used the Operational Standards for Ethics Committees published by the Ministry of Health (2002c) as a framework upon which to construct the ethics application for this study. Guiding principles advocated by the Ministry include: respect for persons, informed consent, privacy and confidentiality, the validity of the research proposal, minimization of harm, justice, and cultural and social responsibility. These principles protect participants in research and innovative practice, and consumers of health and disability services, while achieving consistency in ethical review throughout New Zealand.

In general, older people are a diverse group not considered in need of special protection yet there are two exceptions, older people with cognitive impairment, and those who live in an institution. As people with dementia are deemed to be vulnerable, the context of the proposal was a key consideration. For this reason, a detailed description of the rationale for, and approach to, the study was included in the application. The proposed topics to be addressed included:

- What are the key problems with daily activities?
- What is currently being done to help solve those problems?
- How can increased participation be supported?

Some members of the ethics committee initially raised concerns as to whether or not people with dementia could make an informed choice and whether the choice they made at the outset would remain valid as their cognitive abilities declined over the course of the study. The committee members wanted reassurance that the participants would not be disadvantaged in any way. This sense of caution had been anticipated, and it was a key reason for recruiting a family/whānau member to ensure participants with dementia had the support they might need in discussions. Equally, and for a similar reason, only people in the

early to mid-stages of the disease process were being recruited to offset concerns about the stability of the individual perspective and the accuracy of the information provided by participants. The intention was to monitor participants' willingness to continue their participation during the process of data collection. The Northern Y Regional Ethics Committee approved the study on 10 October 2005 (Appendix A).

To protect the participants, data were kept in a password-protected computer programme and the hard copies in a locked filing cabinet. Upon completion of the transcription process, recordings of the interviews were erased and the remaining data will be destroyed after six years. Signed consent forms were kept in a locked filing cabinet in my home office before being transferred to locked storage at Auckland University of Technology (AUT) on completion of the study. This is in accordance with the requirements of AUT's Ethics Committee (AUTECH) (2001), from whom ethical approval was obtained on 21 November, 2005 (Appendix B).

Participant recruitment

Having people with dementia participate in the study is justified by the philosophy of action research (Kemmis, 2001) and consistent with the critical social theory espoused by Habermas (1984). According to Reason (1998) it is a "fundamental human right of persons to contribute to decisions which affect them" (p. 2). These values underpin the goal of this study which was to understand participants' perceptions of living with dementia with a view to understanding how this influences engagement in daily activities.

Originally I hoped to recruit 15 people with dementia accompanied by a family/whānau member. Knowing that adequacy of sample size is relative in any research (Sandelowski, 1995), I wanted a sufficient number of participants to ensure the information gathered was robust enough to support the findings. Consequently two principles guided the recruitment process:

1. Large enough to generate sufficient data.
2. Not so large as to become unmanageable.

Variation in demographic characteristics such as age, race, and gender, facilitated the collection of a range of data.

Inclusion and exclusion criteria

Since I was looking for evidence to assist people with dementia, I needed participants who had been diagnosed with a health condition which causes cognitive decline and who were prepared to talk about their experience. The criteria for inclusion were as follows:

- Diagnosis of a health condition causing dementia (including the type) by a geriatrician or appropriately qualified health specialist;
- English as first language;
- Person with dementia supported by at least one family member; and
- No other acute illnesses requiring urgent medical attention at the time of recruitment.

Initially I thought it important to specify English as a first language because I knew that people may revert to their first language as cognition declines. In hindsight I realised this was not necessary because I was only looking to recruit people in the early to mid-stages. Similarly, I thought it important that participants had no other major illnesses or potentially life-threatening diseases requiring medical attention at the time of recruitment. This was pertinent because I needed people to participate for the duration of the whole study. At the request of the Regional Ethics Committee, recruitment of people with a diagnosis of clinically significant depression was prohibited by the exclusion criteria. Thus the revised exclusion criteria included:

- Diagnosis of clinically significant depression.
- People in the mid to late stages of dementia.
- Diagnosis of other potentially life threatening diseases.
- Diagnosis of multiple major health issues.

When seeking the support of health professionals to recruit participants, the initial feedback received was very positive. In fact, one leading specialist suggested the research was “*virgin territory*” and “*a study of this nature is long overdue*” (Dr P. Wood, personal communication, 24 March, 2005). Nonetheless, recruiting participants proved to be arduous. The original intent was to have locality organisations or service providers such as the Needs Assessment and Social Care (NASC) team who had agreed to support the research, introduce the study to people with a diagnosis of dementia and their

family/whānau member. An information sheet outlining the purpose of the study (Appendix C) was to be given to potential participants. The plan was to follow up with a phone call, provided the person had given permission. However, three months after receiving approval from the ethics committee, only two people with dementia had been referred. The level of cognitive decline in one person was such that he was not a suitable candidate and the family/whānau member of the other person misunderstood the purpose of the research project and, once informed, chose not to participate. It became obvious, when no participants had been recruited a month later, that the mode of recruitment needed to change.

Fortunately, while attending the Alzheimers New Zealand Conference in Wellington in 2005, I had a conversation with the then president of Alzheimers Counties Manukau (ACM) who expressed interest in my research. Consequently, I was given an opportunity to explain the study to senior staff at ACM and they agreed to actively support my recruitment efforts. I also approached the Auckland District Health Board (ADHB) and Age Concern (a community-based service that works to assist older people), seeking support for the study. In the case of ADHB a further application was required to get approval from its Research Office (Appendix D). On receipt of that, along with Age Concern's confirmation of support, a new application was sent to the Regional Ethics Committee seeking permission to add the new service providers to the original application. Approval was received on 8 June, 2006 (Appendix E).

Participants

Recruitment through ACM brought an immediate response and three couples, Ron and Ann, Greg and Fiona, and Mick and Marianne (pseudonyms) were referred. A call to Alzheimers Auckland Inc. brought another referral, Rita and Bernard, who were very enthusiastic about the study. Then another couple, Scott and Polly joined through word of mouth, and the total number of participants rose to five couples.

Months passed without further recruitment. Data gathering continued with these five couples while I continued seeking more participants. Eventually, in desperation, I followed up a recommendation from Alzheimers Auckland Inc. Early on in the process, a fieldworker had mentioned a couple whom she thought would be ideal, Dutch and Moses.

However, there was a problem in that English was Dutch's second language. Although this was contrary to the original inclusion criteria, he had lived in New Zealand for over 50 years and the fieldworker was very confident of his ability to participate. There is no doubt that my decision to meet with Dutch and Moses was influenced by the fact that the study had been underway for over a year and only five couples had been recruited. Upon meeting Dutch and Moses I knew almost immediately they would play a significant role.

Over the next few months I solicited various community groups such as Rotary, Probus, Catholic Women's League and Carers NZ seeking opportunities to talk about my research. This move was preceded by yet another application to the Regional Ethics Committee to include the community groups in the locality organisations criteria (Appendix F). My goal was to try to recruit participants by word of mouth. Invariably my presentation was greeted with great interest and many people seemed to know of someone affected by dementia. On two separate occasions, I was approached by spouses who were obviously struggling to cope with a partner with dementia. They wanted help and advice, but they did not want to join the research. I did not try to persuade them but responded to their questions to the best of my ability. The community forum succeeded in attracting one more set of participants, bringing the total number to seven. Over time, I eventually managed to recruit a further four couples by word-of-mouth referrals bringing the total to 11 couples. At that point I decided that was a sufficient number of participants. I had been regularly gathering data from the original participants and, as new people joined the study I came to realize I was hearing similar stories and concerns over and over again. For instance, notions of social stigma, loss, fear of the future, and isolation were common, as documented in the literature (McRae, 2007).

Regrettably, the first participant Ron was admitted to residential care towards the end of the second year of the study because health professionals advised his partner Ann, that her health was at risk due to the stress of caring for him. Ron's cognitive decline was rapid and Ann was advised that he was not safe at home alone while she was at work. Consequently, no further data were collected from Ron. Allowing for that one change, 10 couples and Ann remained, as she was keen to continue supporting the study and to share her knowledge and experience.

Stereotypes and ineligibility

In hindsight, I suspect that the difficulties with recruitment may have derived from the negative stereotypes of incapacity that prevail in society. For instance, more than one service provider advised that they had no eligible candidates, and although doubtful, I did not challenge the decision or ask for a rationale. It is interesting to note that three couples who eventually became participants were known to locality organisations who had indicated they knew of no-one who met the inclusion criteria. In fairness, the service providers may have felt they were protecting a vulnerable population, but equally they did not consider that they were unwittingly contributing to the marginalisation of people with dementia. In the critical hermeneutic tradition, this would be seen as a structured and structuring influence on the symbolic assumptions that are tied to social misunderstanding of dementia (Kögler, 1999).

On other occasions, service providers referred people who did not meet the inclusion criteria. For instance, a referral came by word of mouth from a registered nurse. I had doubts about the eligibility of the referred couple at the first meeting, after a second visit I decided their way of life was unsuitable for the purposes of the research. Mary, who had been diagnosed with Alzheimer's disease and her husband John, who had complex health problems were being supported by their son and his wife. A caregiver (from Fiji) was employed to look after both parents during the day because the younger couple led a busy lifestyle. According to the family/whānau, Mary's level of cognitive decline meant she could not participate in any activities of daily living. I decided not to include Mary in the study for several reasons.

1. Her level of cognitive decline was such that she only just met the inclusion criteria;
2. The family's ideas of caring included doing everything for Mary. I felt they were unwilling to encourage her to do what she could for herself;
3. I was concerned the caregiver's cultural background would influence her perception of how to care for people with dementia; and
4. The caregiver's English language skills raised doubts about her ability to understand the purpose of the research.

Although I needed participants, I wanted to recruit people with whom I could communicate and work.

Data collection within family groups/whānau

As Habermas (1971, 1984) has shown, systematically distorted communication and authorized repression are the conditions for claiming an emancipatory interest because without social domination in our lives there would be nothing from which to be emancipated. From this point of view, people with dementia are subjected to forces that reflect negatively on their capacity to engage in life and I wanted to explore this concern with each couple. People's ability to think, understand, and communicate rationally through language defines social thought and human freedom (Kögler, 1999). Similarly, self-reflection guides the recognition of conditions that dominate and inhibit people, whereas the desire to achieve self-understanding and autonomy of action in our lives reflects an emancipatory interest (Habermas, 1984).

Demographics

Of the 11 couples recruited, eight were married, one couple was in a long term relationship, one couple was a mother and daughter, and one was a mother and son relationship. There were six male and five female participants with dementia. Five had young onset, and six were older onset. Time since diagnosis ranged from 15 months to 5 years thus all were considered to be in the early to mid-stage. Two participants lived alone, although one had her home on the same section of land as her daughter. Both participants living alone had daily contact with family/whānau. Of the 22 participants only one was Maori, five were born in Britain, and one in Europe. The remaining 15 were New Zealanders. Five of the family/whānau members were employed, and one of the participants with a diagnosis of dementia was employed part-time. Some were highly educated, others were not. Only one of the participants with dementia attended a community support group once a week, three attended a support group once a month.

Of the 11 participants with dementia, eight had a diagnosis of Alzheimer's disease, two with Lewy Bodies disease, and one with a mixed diagnosis i.e. Alzheimer's/vascular. All had been diagnosed by a suitably qualified health professional. This information was disclosed by the person and confirmed by their family/whānau member. Three were taking *Aricept* and one was trialing *Reminyl*, both of which are cognitive enhancing drugs. The remaining seven were not taking any medications to offset the symptoms of dementia. None of the participants had a history of chronic depression prior to diagnosis, however

following diagnosis, two had been prescribed *Arapax*, an antidepressant, one was taking *Fluoxetine* for depression, and one was taking *Risperidone* for anxiety (See Table 4.1). Physically, all the participants with dementia reported they had enjoyed good health in their lifetime although two had been diagnosed with diabetes in recent years, and two had high cholesterol. Two had word-finding difficulties or would lose their train of thought when interrupted, but could make themselves understood and participate in conversation.

Table 4.1: Participant demographics

Participants	Age (respectively)	Diagnosis	Time since diagnosis	Relationship	Dementia (specific) medication
Ron & Ann	59 & 59 Young onset	Alzheimer's disease	5 years 2 months	Married 1 child	Anti-depressant
Rita & Bernard	75 & 79 Older onset	Alzheimer's disease	1 year 2 months	Married 5 children	Nil
Scott & Polly	62 & 58 Young onset	Alzheimer's disease	1 year 2 months	Married 2 children	Cognitive enhancer & anti-depressant
Greg & Fiona	66 & 63 Young onset	Lewy body disease	3 years	Married 3 children	Cognitive enhancer & anti-depressant
Mick & Marrianne	59 & 58 Young onset	Lewy body disease	2 years 9 months	Married 2 children	Cognitive enhancer & anti-depressant
Dutch & Moses	71 & 71 Older onset	Alzheimer's disease	4 years	Partners No children	Nil
Gran & Pop	65 & 65 Young onset	Alzheimer's disease	3 years 10 months	Married 3 children	Nil
Liz & Mac	75 & 80 Older onset	Alzheimer's disease	3 years 9 months	Married 7 children	Cognitive enhancer
Sheena & Pat	76 & 52 Older onset	Alzheimer's disease	2 years 3 months	Mother & daughter	Nil
Maura & Sonny	76 & 46 Older onset	Alzheimer's/ vascular disease	1 year	Mother & son	Cognitive enhancer & anti-psychotic
Harry & Betty	85 & 86 Older onset	Alzheimer's/ vascular disease	3 years	Married 2 children	Nil

Seven of the participants with dementia reported feeling frustrated by their declining ability to do things and claimed to have experienced a sense of social isolation since being diagnosed. Anxiety was a concern for all family/whānau members and, with the exception of three, all had some form of health issue.

All the participants resided in the suburbs of Auckland, New Zealand. Initial meetings took place in the participants' own homes as that was the most convenient setting and it was envisaged that being in a familiar environment would help them feel safe and confident. To begin with, I met with participants to introduce myself, explain the purpose of the study, and give them an opportunity to form an opinion of me. I wanted a situation in which everyone would feel comfortable exchanging information so that all parties could learn and take action based on that learning.

These meetings lasted between one and two hours. I suspected people with dementia may be sensitive about their symptoms, and so I anticipated that talking about them would make the participant with dementia feel vulnerable. For that reason, I used the first meeting to explain my background and reasons for doing the study. My goal was to create a feeling of trust because I know from experience that innate feelings linger, when topics of conversation are forgotten. Given the sensitivity of the topic, casual conversation was used to facilitate an exploration of their day-to-day opportunities to engage in activities. I wanted to put participants at ease in the hope that it would assist me to capture the cultural, social, and historically-shaped discourses that influence their worldview (Kögler, 1999).

Initial information

In total, over 100 hours were spent collecting data. Initially, I met with the family/whānau groups on three consecutive occasions. The first meeting was not recorded, as I used it to establish rapport and gather demographic information. After these preliminary discussions all the participants were asked to sign a consent form (Appendix G), which included a clause advising that they could leave the study at any time. Personal data were written up on a form I had created based on the concepts outlined in the International Classification of Functioning, Disability and Health (ICF, WHO, 2001) (Appendix H). In the context of health, the ICF has two parts and each part has two components with various domains. Part one considers functioning and disability while part two addresses contextual factors. The components of part one includes body functions and structure, along with participation and activities, while the components of part two incorporate environmental and personal factors. My focus was the participants' physical, mental, and cognitive functions, self care tasks and leisure interests, their personal history, qualifications, productivity and spirituality, and attitudinal, physical, and social factors (See Table 4.2).

In addition, details relating to dementia were documented including diagnosis, by whom, when, and current medications. The intention was to capture as much relevant information as possible about the person with reference to their past roles, habits, interests, values and management of the disease process. As the research progressed I came to realise that gathering this information only from the person with dementia was insufficient because the disease inevitably affects the lives of both participants. I therefore decided it was necessary to document the family/whānau member's profile too. The same ICF headings were used, and health issues replaced the details around dementia (Appendix I). Following the initial meeting, a second meeting was arranged for the purpose of recording data. I also kept field notes of each visit. In these, I noted things like facial expressions and body language, along with my impressions of the level of participation from both people.

Table 4.2
An overview of the ICF

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body functions and structure	Activities and participation	Environmental factors	Personal factors
Domains	Physical, mental and cognitive functions	Self care and leisure interests	Physical, social and attitudinal factors	Personal history, productivity, spirituality

Note. Adapted with permission from the International Classification of Functioning, Disability and Health by the World Health Organization, 2002, Switzerland: WHO.

The conversations, which varied in length from one and a half to two hours depending on the participant's ability to remain focused, were recorded and transcribed verbatim. When pursuing a methodology of critical interpretation it is necessary to ensure that the dialogic process of gathering data includes the circumstances through which meaning is constructed, so that the things that shape the participants' understanding (their worldview) are revealed (Kogler, 1999). This was taken into consideration during the interview process and whereas I began with a semi-structured list of questions (Appendix J) to guide the interview process. During the discussions I also asked probing questions such as:

1. How did that make you feel?
2. What exactly makes you feel that way?
3. Why do you think that?

4. Why did you say that?
5. Where specifically did that idea come from?
6. How do you know that's true?

As I became more practiced at drawing out information I changed my approach. For instance, I came to realise that asking questions such as:

1. Are there problems when you try to do daily activities?
2. Have you done anything to help solve those problems?

was inept, as I was expecting people to confront the implications of the diagnosis and assuming they had problems. Since there is a lot of uncertainty about what a diagnosis can mean, instead of asking about problems arising from the symptoms, I changed the questions (Appendix K) to include:

1. How do you spend your day?
2. Do you notice any changes in your lifestyle?

Changing practice

The first action component of the research can be found in the attitudinal shift that I encouraged during the discussions. For instance, I argued that by remaining silent, people with dementia were living down to other people's expectations when they should make every effort to live life positively. Urging participants to speak up for themselves was intended to stimulate change in other people's understanding of dementia. *"We've talked about people in society needing a greater understanding and acceptance, but it seems to me that won't happen unless those with Alzheimer's speak about it to people they meet."* Following this approach I became conscious that I was not the one having to deal with this reality and realised that it is easy to advocate a course of action when not having to undertake the action. (See Appendix M for further explication of the action research cycle underpinning this account). According to Kemmis (2009), this type of goal in action research is "a practice-changing practice" (p. 464). In addition, on more than one occasion when advice was sought on practical problems arising from cognitive impairment, I was able to offer a useful solution. Thus, I advocated that actions should and could be different.

At the end of each conversation I made a point of asking if there were topics I had not considered but which should be addressed. I wanted to ensure the participants could contribute to the knowledge that was revealed. The key areas I explored were:

1. Participation in daily activities.
2. Issues around participation.
3. Changing abilities.
4. Practical solutions.
5. Environmental considerations.
6. Time management.
7. Support needs.

The participants led the flow of dialogue and so were able to take the conversation in any direction, provided it was related to the experience of living with dementia. Often they would veer off track and at times I let the conversation drift briefly before bringing it back to the topic of discussion. Towards the end of the conversation I scanned the topics to ensure all the questions had been adequately discussed.

When I started out on this project I was not sure what I would learn or what action would evolve from engagement with participants. I had a firm belief in the role of occupation in underpinning health and I had some vague notions of how occupational therapy knowledge could be used to assist people who live with dementia to engage in daily activities. As I became more adept at delving for information I realised that some of the data I was gathering were of no consequence since most of the participants managed to cope with the small problems they encountered doing daily activities.

It soon became apparent from listening to the participants that the loss of social connections and the lack of support systems had a major impact on their lifestyle. This caused me to reconsider the questions I was asking, to reflect again on what I had been hearing from participants and reading in research literature before collaborating with three participant couples individually to develop a further set of questions. This is consistent with the process of reflection and action that is central to action research (Reason & Bradbury, 2006). The goal was to identify new questions to facilitate the discussions and not to direct them. As a result, the data were enhanced by adding another dimension. The focus was still daily activities but this time the questions included:

1. Can you tell me what it is like for you having this disease?
2. What effect has the disease had on your lifestyle?
3. Do you have any thoughts on what type of help you would like to support you?

After the initial visits, I usually let three or four months elapse before contacting individual participants again. I wanted to capture experience over time. Almost from the beginning, it was clear that even though the participants were capable of voicing an opinion, some of the participants with dementia seemed to lack insight into the ways in which dementia had affected their ability to engage in daily activities. Consequently, there were times when responses were not quite accurate according to the family/whānau member who also gave their interpretation of reality. Many of the questions were pertinent to the family/whānau member too. Including family/whānau in the research has therefore contributed to the richness and diversity of the data. Validating the key issues is consistent with the principles of action research. Focus groups provided another opportunity for similarities and differences in opinions to be revealed, leading to further reflection and action.

Focus groups

According to Morgan (1997) individual interviews and focus groups complement one another. While individual interviews are known to produce more in-depth information and detail, focus groups have the distinctive ability to provide access to data that is not easily obtained in individual interviews (Krueger & Casey, 2000). Consequently, when data gathering reached a point whereby information redundancy (known as saturation in ethnographic and grounded theory research) had been achieved, eleven participants were invited to take part in focus groups to consider the constitution of knowledge (Krueger & Casey, 2000). That is, by sharing the insights I was developing, the participants engaged in the production of knowledge by guiding me in determining what was important and what was not.

Six to eight people is the recommended number to ensure a focus group is manageable and the findings are credible (Krueger & Casey, 2000). More were invited to allow for non-attendance including Ann, Mac and Liz, Dutch and Moses, Rita and Bernard, Mick and Marianne, Greg and Fiona. The community room at a local library was ideal for the focus groups as it is centrally located, small and quiet with no distractions. The eleven invited

participants lived within a reasonable proximity so it was hoped that the convenient location would encourage them to attend.

The discussions

Having facilitated focus groups in the past, I had some knowledge of the process. I wanted the gathering to be relaxed, not contrived, and felt confident about my ability to stimulate discussion. The first focus group was held in 2007 and my initial approach to the nine participants who took part was informal. I greeted everyone personally and made introductions as required. Casual conversation kept those who arrived first occupied while we waited for others to come. By now I knew the participants quite well and some knew each other from their involvement with Alzheimers New Zealand Inc. Surprisingly, the spouses of two participants knew each other from their school days and had only met once or twice in between so they were soon deep in conversation. Four couples and one caregiver participated (Dutch and Moses, Rita and Bernard, Mac and Liz, Mick and Marianne, and [on her own], Fiona). There was a relatively equal distribution of people with dementia, caregivers and male/female attendees. Three of the participants had older onset dementia and one had young onset dementia. The spouse of the caregiver who came on her own had young onset dementia.

Following the guidelines set out by Krueger and Casey (2000), prior to commencing both focus group discussions I established ground rules to try to ensure everyone had an opportunity to speak. I then reiterated the purpose of the group, before giving an overview of the study to date. Finally, I reminded everyone that the tape recorder in the centre of the table would record our conversation. The proceedings of the first focus group began with an introductory question which was intended to direct the participants towards the topic before moving on to a transition question. The questions which followed were designed to explore similarities and differences in the participants' experience of living with dementia.

Introductory question:

1. People have talked about the shock of receiving a diagnosis of dementia. Is there anything you'd like to say about that?

Transition question:

2. People have talked about a normal lifestyle. Would anyone like to explain what that means to them?

Key questions:

3. Tell us about your experience of living with dementia?
4. Can you talk about the challenges, the positive and negative aspects of living with dementia?
5. What is helpful / what is not helpful?
6. Do you have other ideas of what would make it easier to do the things you want to do?
7. What happens as a result of other people's attitude?
8. Is there anything else you'd like to say?

These open-ended questions were interspersed with prompts to keep the conversation flowing and/or to explore opinions in greater depth. For instance, 'can you tell us more about that'? or 'can you describe how / what / where?' The questions were intended to add depth to my understanding of their experience. Language was deliberately kept simple to investigate the connection between all elements of the experience with a particular focus on occupation, the person, and the environment. There was an assumption that occupation emerges from interaction between people and the environment (Kielhofner, 1995b).

A second focus group was convened late in 2008 to facilitate more in-depth discussion of the themes arising from the preliminary findings; formative, summative, and unexpected. On this occasion 13 people agreed to attend including Greg and Fiona but then they withdrew because of another commitment. Six of the eleven participants had also attended the previous focus group. Those present included five couples and one caregiver (Dutch and Moses, Rita and Bernard, Mick and Marianne, Gran and Pop, Scott and Polly, and Ann) with a gender mix of six men and five women. Two had older onset dementia and three had young onset dementia. The spouse of the solo caregiver had young onset dementia.

Presenting the categories for discussion, the second round of data collection and analysis in the action cycle, gave the participants an opportunity to explore, identify and reflect on the preliminary findings. Questions related to these findings were intended to elicit

participants' opinions. I tried not to lead or guide them so there were times when the conversation deviated from the topic. For instance, variance in the cost of *Aricept* was discussed with keen interest. Sources of supply were exchanged before the conversation came back to the research, thus participants were also able to use the focus group to serve their own purposes. Some participants initially seemed hesitant to join the discussion, there was an aura of uncertainty in their responses however, and others took the opportunity to expound. As time went by, the content of the conversation became richer and participants felt more able to speak freely, giving voice to their opinions.

Both groups lasted around two hours and only came to an end because the venue was due to close. The participants remained attentive and focused throughout and wanted to talk further, even when I was trying to bring the discussions to an end. This unexpected response indicated that the participants felt empowered by participating in the group and talking to others who share similar problems (Bryden, 2005; Friedell, 2003a; Taylor, 2007). Krueger and Casey (2000) proposed three types of ending questions:

1. The "all things considered" question, which allows the participant to voice a final opinion (Krueger & Casey, 2000, p.45). "All things considered, what are the key things that you would like people to understand?"
2. The summary question comes after the interviewer has summarized the discussion. I identified what I perceived to be the key points repeated in the discussions before asking the participants to comment on the summary. All agreed with my précis.
3. The insurance question is intended to ensure that all critical aspects of the topic have been covered: "Are there any other things that we should have covered?" This was an important question as it provided an opportunity for participants to raise issues / questions that I had not considered. No suggestions were offered.

After the formal discussions had ended, the conversations continued. Krueger and Casey (2000) recommended leaving the tape recorder running at such times to try to capture additional, unintentional data. I did this initially but was not comfortable with the recorder running unbeknownst to participants and so I turned it off. When making field notes later I recorded observations and considered aspects such as: Was the group successful? Why? Was there a consensus of opinion? What was surprising?

Transcribing the data

Initially, I personally transcribed the audio-taped data verbatim, beginning immediately after the first couple was interviewed. Revisiting the recorded conversations enabled me to focus on details that might otherwise have been missed (Denzin & Lincoln, 2003). In listening, I could hear again participants' times of uncertainty in the way they would voice an opinion or make a statement and then check the details with family/whānau. Repeated listening to the recordings sometimes revealed previously unnoticed features recurring in the conversations. Importantly, I also learned how to reframe questions to enhance understanding and what questions to leave unasked as they were unhelpful.

As the number of participants increased, I enlisted the aid of a transcriber. Participant privacy was respected inasmuch as first names only were used on the tapes. Once the conversations had been typed, I went back over the recordings to make sure nothing salient had been left out and to reacquaint myself with the data. I knew I was immersed in the data when I was able to carry conversations in my head and reflect on them as I went about other activities. Being able to recall relevant details helped to highlight important connections between conversations. Key factors slowly emerged through reflection and note-taking. This is consistent with the action research process of generating knowledge.

Generation of knowledge

A detailed description of how to approach data analysis in action research is not readily available, since no one set of principles or methods apply (Reason, 1994). Data collection informs the data analysis and vice versa so the two processes become reciprocally integrated. Consequently, the move from data gathering and analysis to feedback and discussion, to action and evaluation of the action did not follow a rigid methodological procedure. Instead, the process was responsive to the feedback received from participants in relation to the understandings I was reaching, as well as accounts of their experience of living with dementia. This allowed the cyclic process of action, reflection, modification and further action as advocated by Lewin (McTaggart, 1997). This approach is argued to increase the internal validity of the results and therefore strengthen the scientific evidence (McNiff & Whitehead, 2006).

A critical interpretation

The philosophies of critical hermeneutics which underpin this action research facilitated an exploration of everyday problems people with dementia face in relation to issues of power, justice, and democracy. Understanding the potential connections between actions and social values is a central aspect of analysis because it takes into account the ways in which people connect their everyday experiences to the ways in which those experiences are socially described. Revealing ideologies hidden in social customs can be complicated by the typically imperceptible ways unspoken meanings are circulated into daily life (Habermas, 1989; Kögler, 1999).

In the critical hermeneutic sciences, knowledge is known to be shaped by the social, historical, cultural, and the linguistic context in which the interpreter functions. The notion that every interpretation is grounded in a particular context, and every context may be infused with previously unrecognized power structures, can pose a problem for a critical interpretation (Kögler, 1999). This raises the question of how the researcher can overcome, yet draw on, personal preunderstanding to analyse and critique power-saturated meaning structures. In the belief that the interpreter's preunderstanding is historically situated, and ever changing, Kögler (1999) argued that the "thematized focal points" (p. 106) or the way in which data were interpreted, the concepts which enable one to reach understanding, all have to be analysed in relation to personal, social, and discursive structures of power.

Identifying "undetected power complexes" (Kögler, 1999, p. 106) would help to reveal the forces that shape the reality of living with dementia. Realizing this made it easier to understand and accept the social construction of reality from the viewpoint of the participants. Additionally, recognising that as the researcher I could not know the experiences of each participant allowed me to accept the limits of my role. Nonetheless, I needed to be able to relate to their experiences to gain understanding of their perspectives. My learning throughout the various stages of data collection, reflection and analysis was ongoing, and equally, an exchange of information was valued by participants. I was pleased to be able to share knowledge and experience from my practice of occupational therapy in response to their questions, in addition to lending books and other literature as required to enhance their understanding of a specific topic.

An important insight in unfolding the participants' experience of dementia is that the general features of the discussions utterly depended on my interpretation of their personal experiences. This is crucial since individual attitudes are capable of showing implicit meanings and substantive judgments in a critically advantageous way. According to Kögler (1999), understanding meaning from the perspective of participants should enable an interpretation which identifies their values.

To overcome issues relating to the interpreter's preunderstanding, Kögler (1999) encouraged a reconstruction of the interpretive effect of self distantiation, so that participants become the point of departure for critical insight into the data. His conception of critical hermeneutics supported amalgamation of the participants' views, assumptions, and practices to trigger a process of self-reflection. In this way, hitherto hidden aspects of understanding can be revealed, giving the interpreter the freedom to distance him/herself from taken for granted assumptions and practices. Kögler (1999) considered this necessary to make possible "a critical understanding that goes beyond and gets behind ...our own norms" (p. 109). He acknowledged that such an insight can never be pure, context free, or absolute, nonetheless when adequately developed this insight into the other's perspective can be all the more valuable because it introduces knowledge that could not have been generated in any other way.

The significance of the participants' voices is fundamental to the production of knowledge and understandings that have been illuminated in this study, likewise, the relevance of personal knowledge to the shaping of the interpretations. In the initial stages of the research, much of the action component comprised personal self-reflection on what I was doing. I found myself questioning the ideas and beliefs that influenced my thinking as well as checking my own taken-for-granted assumptions. By deliberately challenging my personal values, I was constantly aware of the need to focus on tuning into the participants' values and assumptions. In subsequent meetings, my thoughts on the data and emerging categories and themes were shared and discussed in an ongoing manner. Engaging the participants in this important facet of interpretation ensured that their voices were heard more than mine.

An overview of data analysis strategies

The process of critical hermeneutic data analysis had several stages, each of which was informed sequentially by the action research cycle. An overview of that process and its guiding principles precedes the detailed description that follows. As the number of participants grew, similarities and differences in the data became apparent and upon reflection I began to see how fixed ideas and social structures influenced the participants' daily lives. Initial codes were noted on the transcripts and interpretations were discussed with the participants at the next meeting to make sure I had accurately understood what they were telling me. Stigma permeated the transcripts and thus became one of the first codes. Isolation was another.

Reflecting on the codes and discussing them with participants and supervisors, the first stage of analysis, led me to see the connection between stigma and a myriad of attitudes. It's not only other people's attitudes, but personal attitudes towards living with dementia, the carers attitude to caring for someone with dementia, and social attitudes relating to what a person with dementia can and cannot do. All of these attitudes influence how people with dementia navigate their daily life and once I grasped this, attitudes became a category. The reflexive, cyclical process of analysis included reading and rereading the transcripts, reflecting on the initial codes, working across transcripts to see if new insights were applicable to other participants. The second stage of analysis helped to answer my own questions regarding the adequacy of the categories. I mind mapped ideas making links to philosophy, the topic, and the research question. I discussed new ideas with participant dyads and focus groups; wrote down thoughts to share with my supervisors. The codes were grouped and regrouped into categories before becoming initial themes. During the third stage of analysis I read literature and challenged myself to find different ways of thinking about the data. I did not use a qualitative software programme for analysis because if I was to be true to my claim of listening to the participants voices, then they needed to participate in analyzing the data. (See Appendix M for further explication of the action research cycle underpinning this account).

According to Kögler (1999) consideration of the parts in the data is the dynamic which brings the themes into focus. Although inter-connected, the themes are separated out to bring to "conscious awareness the underlying premises of...interpretive praxis" (Kögler,

1999, p. 11) and to explain the “undetected power complexes” (Kögler, 1999, p. 106) that influence the lives of the research participants. To bring out the themes in this study, the data were explored back and forth with respect to the whole and the whole in relation to the parts. Referring to power complexes, Kögler also posited that the way findings are thematized, the concepts which enable one to get hold of them, the “thematized focal points” (p. 106) all have to be comprehensively analysed in relation to individual, social, and discursive power. Accordingly, further critical reflection was undertaken to work out the historical and social dynamics shaping my initial interpretation. To find ways to assist people who live with dementia to engage in daily activities it was necessary to consider all the issues that prevented participation and to work out the root cause of those issues. The interpretation was not finalized until all the participants had been consulted individually and there was a consensus of opinion from the focus group discussions. The format used to present the analysis is drawn from the work of McAra- Couper (2007).

A three stage analysis

Stage one of the analysis involved reading the transcripts thoroughly and noting codes before rechecking with participants to confirm my interpretation. This stage focused on identifying the world-views of the participants (their understanding of their experience). The goal was to reveal the challenges that beset people with dementia and their family/whānau when they engage in daily activities. To that end, codes were used to classify similarities or common threads running through the data. This was done by grouping the data under the headings: problems, attitudes, stigma, needs, time management/use, expectations, safety issues, and social connections. It was important to show something of the discursive framing before this was shared with participants for critique, clarification, verification, and evaluation. A systematic classification of initial codes revealed a deeper significance and provided a new way of understanding.

Kögler (1999) argued that speech is formed into discourses when it precedes the content of statements through which the ontological presumptions of theories are made possible with respect to thematic concepts. The data were therefore shaped through analogical thought to uncover the unspoken and unstated assumptions which shaped the discourse in the first instance (Kögler, 1999). This involved reflecting, processing, and writing down thoughts that the data had generated, to enable a clear articulation of the categories being explored.

The process of refining the categories was initially undertaken during individual meetings with participating couples and repeated again during the focus group meetings. Recurring codes were re-coded as categories with relevance to an emerging theme. In this way the world-views of the participants were identified along with insights into the ways in which their view had been shaped. This method of analysis is recognized as fitting the all-purpose measures for analyzing and reporting data (Morgan, 1997).

Stage two involved using philosophical underpinnings to reveal the ways in which meaning and world-views are shaped. A number of categories emerged during the early stages from the perception of both the person with dementia and family/whānau members. A critical perspective was used in discussions to make the categories more congruent with critical hermeneutics. At this stage, the analysis had four layers under the headings: participants' worldview; social theories; discursive symbolic assumptions of difference; and power as knowledge. The following illustration provides an example:

1st layer: Participants' worldview

This layer was explored through a critical hermeneutic lens. An example of a worldview which showed itself in the data regarding attitude is evident in the following participants' comments:

- *"If it's my problem then I should be able to speak about it."* (Rita).
- *"I have a right to be treated as a whole human being."* (Greg).

2nd layer: Social theories

A critical hermeneutical lens was again used to make known world-views in this layer. The negative attitudes towards people who live with dementia revealed social stigmata congruent with critical social theory. Examples included:

- A person with dementia has lost their mind.
- There is no hope with dementia.

3rd layer: Discursive symbolic assumptions of difference

Critical analysis at this point focused attention on the influences that shape social practices, while constituting and creating meaning. For example:

- Both personal and societal attitudes make a difference to the ways in which people with dementia engage in daily activities.
- Different people have different attitudes: positive, negative, patronising.

4th layer: Power as knowledge

Synthesizing the preliminary themes with philosophical literature helped analyze and explore the complex connection between power and knowledge in the action research process. Some of the structures that were identified as shaping attitudes towards people with dementia include: monopolies of power; deep-rooted power inequities; and power relationships between individuals, especially those involving professionals. For instance, staff who adopt the attitude of their employing organization or hold a position of power as service providers.

Since the theory out of which the discussions emerged was intended to improve knowledge and bring about change, initial ideas were not enough. A much broader development required opening up the preliminary themes to more in-depth discussion in the larger group context. This made possible a deeper development of the findings so that the things that generate meaning in relation to living with dementia could be grasped.

Stage three involved synthesizing the data and associated literature to show the relationship between power and dominance. Repeatedly reading the data and initial writings helped to capture a sense of the bigger picture emerging. From the beginning of the study, literature from a variety of disciplines including occupational therapy, nursing, psychiatry, psychology, philosophy and sociology was read to gain insight to the ways in which knowledge is produced. In addition, professional journals and newspaper articles reporting new research developments contributed more knowledge. The purpose of such diverse reading was to ensure a thorough and up-to-date understanding of the beliefs which discursively frame other people's understanding of what it means to live with dementia. Up to this point the analysis felt messy. Forging a link between the data and the reading material provided a means of describing the constitution of understanding.

Drawing from similar and divergent understandings and ideas, and the evidence or theories that inform them, opens up a space in which the things that shape understanding can be

discovered and described (Kögler, 1999). Here again I draw on a framework developed by McAra-Couper (2007) to elicit the participants' opinions, views, and ideas and thereby create a reflective space in which the influence of power on their understanding could be revealed. The goal was to link the philosophical and methodological underpinnings of critical interpretation with the data for the purpose of analysis. Kögler provided philosophical insights which shape this stage of data analysis with regard to emancipation, power, domination, social practices, symbolic order, distantiation, and reflexivity. The framework which follows was designed to link the philosophical and methodological underpinnings of critical interpretation with the data for the purpose of facilitating analysis.

What is the worldview (reality) for the participant?

What does this worldview pre-suppose in terms of what a culture/society/people value?

Where does the authority for this understanding/practice come from?

What specific rule systems delimit what can be stated and what is accepted?

What is not acceptable for the participants?

What has become acceptable for the participants?

What are the specific rule systems which give meaning to the participants' understanding?

What is shaped as a result of these rule systems?

What is shaping this reality? (McAra-Couper, 2007, p. 84)

This method of data analysis shows how taken-for-granted assumptions, habits, customs, ideology and tradition, and symbolic orders insidiously pervade understandings and preunderstandings to shape social perceptions. Kögler's (1999) theory of knowledge production provided a way to clarify the sometimes vague and uncertain interpretive process. Furthermore, it facilitated deeper understanding of the hidden structures and tacit forces that prevail in society and produce actions that subtly affect attitudes towards people who live with dementia.

Input from the participants both during discussions with couples and the focus groups had determined what was important in the data and what was not, what was to be given attention, and what could be ignored. During the second focus group the preliminary findings were presented to facilitate more in-depth analysis. These included the formative, summative, and unintended findings. Taking into account the knowledge production going

on in the focus groups facilitated a further round of reflection, action, and evaluation. Combining interpretation with rigorous testing distanced the interpretation from my social and historical beliefs to improve the credibility of the research.

The constitution of good quality research

The quality of action research lies in its validation process. This can be strengthened through a reflexive process which reveals preunderstandings and prejudice (Waterman, 1998). Constantly reflecting on, questioning, and evaluating the research process facilitates understanding of how subjective and inter-subjective elements may have permeated (and possibly transformed) both the data collection and the analysis (Finlay, 1998). Reflexivity was integrated into action research based on Schön's (1995) notions of reflection-in-action (cited in Rolfe, 1996). Finlay (1998) described reflexivity as a "thoughtful analysis" which involves "continual evaluation of both subjective responses (personal reflexivity) and the methods of the research (methodological reflexivity)" (p. 453). This action process was incorporated into my reflections on group discussions, in which I was a facilitator and participant, as well as evaluations following each stage of analysis and action.

Habermas (1984) argued that in order to understand what the participants are saying, the researcher has to be familiar with the validity or trustworthiness of their claims. Furthermore, Rolfe claimed that the quality of research should be judged by the researcher / practitioner as the most qualified person to interpret the findings. On these grounds, my considerable experience of working with people with dementia and my knowledge of occupational therapy practice have enhanced the validity of this research.

Establishing validity

Many academics who have come of age during the evolution of action research focused their scholarly attention on validating its epistemology (Bradbury & Reason, 2006; Kemmis, 2001; Winter & Munn Giddings, 2001). Frustrated by forms of domination that emerged from the positivist paradigm; these scholars saw action research as a method of freeing academic work from systems of power. Impressed by the potential of action research to offer new understandings of the relationship between ideas and practice, academics wanted to contribute to the development of new ways of thinking about validity and quality in research. For reasons such as this Fals Borda & Rahman (1991), and others (Gustavsen, 2008; McNiff & Whitehead, 2006; Waterman, 1998) argued that a profusion of

validities emerge from the context of each specific action study. Nonetheless, Morton-Cooper (2000) warned against undertaking action research for academic purposes. One of the key problems she identified was that of convincing examiners of the merits of the methods used.

That may be why Bradbury and Reason (2006) presented five broad issues concerning the validity of action research. Based on ‘choice points’ which are said to be the core of action research, the issues include relationships, practical outcomes, extended ways of knowing, purpose, and enduring outcomes. No action research can address all these issues equally so choices must be made about what is important and what is not in the emergent and messy work of analysing action research (Bradbury & Reason, 2006). These issues will be considered in the discussion chapter of this thesis. Essentially, validity is about establishing the truth value and rationality of communication (Habermas, 1984; McNiff & Whitehead, 2006; Waterman, 1998). According to Bradbury and Reason (2006), the clarity with which choices made during the action research process are presented, is a solid starting point for establishing the rigour.

A question of rigour

Literature across disciplines advocates that good research requires researchers to make processes visible to allow for methodical scrutiny (Creswell, 1998; Guba & Lincoln, 1994; McNiff & Whitehead, 2006; Silverman, 2000). Rigour is an important component of intellectual honesty and relates to clear evidence of meticulous attention to detail in the process of a research study (Friedman, 2001). Four categories have been identified as relative to the rigour of this study including: credibility, fittingness, audibility and confirmability (Taylor, 2006). ‘Credibility’ is established by the participants’ and readers’ levels of confidence in the truth of the findings. If the experience can be recognized from the text then credibility is attained. ‘Fittingness’ means the findings of the research are applicable to other similar experiences. The term is also used to represent the extent to which readers find it has meaning and relevance for their own experience whereas ‘auditability’ refers to the decision trail of the research which shows it has followed a scrupulous methodological process. ‘Confirmability’ is possible through demonstration of the first three characteristics provided they are subjectively confirmed by the participants (Taylor, 2006). These categories are underpinned by Habermas’s (1984) concept of validity

whereby participants confirm the truth and rationality of theories as relevant to their experience through discourse. When the participants confirm the data are a true and accurate record of conversations during group discussions they distance the researcher.

Several methods and processes were employed to enhance the credibility of this study, including the interview technique, member checking, peer examination, and reflexivity. I recorded my reflections and observations of participants' actions and body language while engaging in daily activities to add more depth to the data (Appendix N). Discussing findings progressively with participants and going back over what was said at previous meetings for confirmation or correction was another action used to establish credibility.

In terms of fittingness, or the extent to which the findings of the study can be applied to other people with dementia, it is important to remember that in all facets, both action research and dementia are unique experiences. Nonetheless, it can be said that fittingness was tested on a number of occasions. For instance, following a conference presentation at the University of Stirling in Scotland, which was attended by people with dementia, caregivers, and health professionals, one delegate who lives with dementia approached me and said with a smile "I have a complaint...you said all the things I want to say" (James McKillop, personal communication, 3 September, 2008). Further discussion revealed that the content of my presentation resonated strongly with his experience. A rich description of the people in the study and the methods used has been provided so that others can judge the auditability of the findings.

Summary

This research project was constructed and reconstructed through the cyclical processes of action research and in response to three sets of interests: those of the researcher; those of the participants; and those of socially dominant political structures, organizations, and social groups. The process, including the study design, my role within it, the method of data collection and data analysis, has been outlined in this chapter along with criteria for judging the quality of the research and the validity of the processes used.

The findings in the chapters which follow describe ways in which people with dementia who live in the community, can be supported to engage in daily activities. It is essential to

acknowledge at this point, and to keep in mind while reading these findings, that a number of views presented themselves during the study in relation to living with dementia. Only the key points prioritised by the participants are explored in greater depth for the purposes of this thesis. Therefore to fulfill the purpose of the study, the social construction of dementia is explored by means of three key findings; The nature of Being in the world with dementia, Difference, and Prejudice and power.

Chapter Five

The Nature of Being in the World with Dementia

“Language is the house of the truth of Being”

Heidegger (1889 – 1976)

The nature of ‘Being’ in the world with dementia takes many forms. Heidegger’s concept of Being in the world was further developed by Hans-Georg Gadamer who raised anew the question of how understanding is possible. This draws attention to the notion that linguistically constituted meanings can accommodate the truth of what it means to live with dementia. If we understand meaning, then we presume more than just an internal symbolic unity and accept the truth of what is said. Reflecting on truths opens up possibilities for action. This chapter charts my progress from initiating the study, to learning from participants as they learned from me, to actions taken early in the study.

In presenting what was learned overall, it is important to acknowledge that each participant spoke from his/her own perspective and that although the nature of brain damage caused by a disease such as Alzheimer’s may in some respects be similar, the way in which the symptoms are manifest varies greatly from person to person (Sabat, 2001; Snowden, 2001). Equally, since each person has different experiences and approaches to living, knowledge of the person’s history and the influences which have shaped his/her way of being is as important as knowing the extent of neurological impairment (Banerjee, 2005). Thus, autobiographical details are a rich source of information and form the groundwork for understanding how people live with dementia. Accordingly, in the process of presenting the findings, personal data is provided to give an insight into the individuality of each person. Along with an account of their daily activities, a rich description of verbal and non-verbal communication (world-views) is presented to contextualize the understandings contributed by each participant in the study. This will be followed by a critical analysis of the data to “make present the implicit operation of power” (Kögler, 1999, p. 107).

The initial phase of analysis was guided by Kögler (1999) who, influenced by the early work of Heidegger, alleged that we will only come to understand something as something “when the entities within the world are discovered along with the Being of Dasein” (p. 89).

In attempting to understand the being of Dasein, I first needed to understand the concept of Dasein. Early in his career, Heidegger sought to discover the meaning of Being (Dasein) or reality of human existence (Grenz, 1996). Understanding the notion of Dasein in this way raised other questions: What is being? What am I? How did I come to be? What does my existence mean? (Grenz, 1996).

Philosophical insights

In addressing these questions I will draw from Gadamer's ideas on understanding, language, interpretation, lifeworld, and horizons throughout this chapter. In seeking to develop a new understanding of Being, (Gadamer, 1993) argued that "Understanding belongs to the being of that which is understood" (p. xxxi). What is more, he claimed that understanding is aligned to the whole of our experience of coming to know the world. Therefore, uncovering meaning and understanding is dependent on the 'situatedness' of the interpreter and the person (or text) they seek to understand (Grenz, 1996).

Drawing on the work of Gadamer

In presenting his theory of Being, Gadamer's assertions have far-reaching implications for the meaning of reality as a whole. "There is no pre-existing meaning 'out there' rather meaning emerges as the interpreter engages in a dialogue with the 'text' of the world" (Grenz, 1996, p. 111). Gadamer (1993) followed Heidegger in suggesting that human Being is thoroughly in the world. Being in the world means we can never escape a historical context. When we stand in different places in the world, we naturally develop a different point of view on the world and different interpretations of the world. Yet because of the common aspects of being in a world with similar traditions and language, a fusion of horizons is possible (Grenz, 1996).

For just this reason, to understand the reality of living with dementia it is necessary to find the answers to questions such as: What is the meaning of being with dementia? How is dementia experienced? What is it like to live with progressive dementia? Only when we seek it in reality will we understand the experience. To do that, we need to look beyond the person and the diagnosis, and to recognize the inextricably dynamic interaction between the person, dementia, and context. Referring to dementia in the context of illness Gadamer (1996) advised that, "It is clearly a misrepresentation to look at the concept of illness

solely...from the standpoint of scientific medicine, and to think that medical knowledge is the same thing as the patient's own self understanding" (p. 52).

Seeing the participants' perspective

People's responses to the symptoms of dementia are variable but they are always influenced by both personal attitudes and the attitudes of others in society. Attitudes influence the way people see things and there are many ways of seeing; we can see positives and/or we can see negatives. Both are there and what we choose to focus on and to see will result in feelings of satisfaction and/or feelings of despair (Mulholland, 2005). Understanding this means simultaneously grasping the positive aspects as well as the negative ways in which the disease has affected the person. What we 'see' will affect how the person is treated and, how their abilities are acknowledged and supported will, in turn, affect how they respond (Sabat, 2001).

Other people's attitudes were important to the participants in this study and most alluded to the influence of attitudes in the first conversation. Sometimes it was in response to a question I asked and sometimes it was unintentionally provoked. For example, during my first interview with Scott, I revisited the purpose of my research and asked him if he was comfortable talking about his diagnosis. He said "*of course - no problem.*" Yet it very quickly became obvious that hearing the word *dementia* irritated him. He told me in no uncertain terms he did not like the "*label*" and would prefer I did not use it. Interestingly, I immediately thought I understood why. When I asked Scott why he did not like the word he stated: "*It's to do with disassociation*" by which I interpreted him to mean the disintegration of cognitive function. When asked what he would like me to say he indicated he could cope with the word Alzheimer's, but he did not like the word dementia. Eventually, I came to believe that Scott's aversion to the word *dementia* was based on a social construction of meaning which is commonly taken for granted (Snowdon, 2001).

My understanding of the word *dementia* is grounded in my socially-shaped preunderstanding of something that people who live with dementia constantly endure, namely, the stigmata and stereotypes associated with the word. Drawing on the work of Gadamer, Kogler (1999) argued that understanding is not possible without preunderstanding. Further, he stated that every interpretive act is made possible by a largely

implicit preunderstanding. Accordingly, my experience of working with people with dementia, coupled with knowledge gained from the literature has shaped my preconceptions of what I perceived to be the fear and shame of having dementia.

Encountering emotions

Fear of dementia is understandable given that the prognosis for someone diagnosed with dementia is usually characterized by a progressive degeneration of brain function. The slow decline is associated with significant impairment in social and/or occupational functioning, and/or behavioural changes (American Psychiatric Association, 2000). Today's society emphasizes and rewards high-level fast thinking and action, so it is easy to understand how the stigmata and stereotypes associated with dementia are power structures which imprison people with dementia with ideas of who they are and what they can and cannot do. Indicative of social disgrace, stigmata lead to marginalisation, whereby people with dementia are set apart from the rest of society because other people make assumptions about their abilities. Negativity is manifest in words like 'a living death' or labels such as 'out of their mind' (Zeisal, 2005). Such attitudes have a profound effect on both personal and societal perceptions, resulting in fear of the unknown and shame at the loss of social identity (Sabat, 2001).

Of equal significance, shame is variously defined as an emotion, cognition, a state, or a condition (Collins Concise Dictionary, 2001). A sense of shame relates to being aware of shame as a state or condition. Shame may be also be assigned externally, by others, regardless of one's ability or awareness (Oxford English Dictionary, 2008). A feeling of shame usually occurs as a result of any situation of embarrassment, dishonour, disgrace, inadequacy, humiliation, or annoyance resulting from a violation of cultural or social values (Oxford English Dictionary, 2008). This feeling is particularly relevant because cognitive decline is commonly perceived to be socially abhorrent (MacRae, 2007). People in society readily understand and accept the effects of physical health problems, but they do not have the same empathy for those with cognitive or mental health problems.

Scott was not the only participant who voiced concern over the indignity of the word dementia; other participants were equally sensitive. Some said they did not tell people about their health issues because it was no one else's business and even those who said they are quite open about it with friends were not really as open as they believed. Most of the

participants were reluctant to tell others about a diagnosis of Alzheimer's or similar type of disease because they feared a change in attitude. Referring to time spent in a prisoner-of-war camp, Frankl (1964) stated that "Everything can be taken from a man but one thing: the last of the human freedoms - to choose one's attitude in any given set of circumstances" (p. 65). This notion was endorsed by Mulholland (2005) who stated "It is not what happens to you that is the problem, it's your attitude to it that's important" (p. 20). Whereas Frankl and others in his position at the time could, albeit tentatively, hope for a better future, the current prejudices relating to dementia are embedded in social structures that are insurmountable in the everyday world and leave little or no hope of a better future.

When living with dementia, freely choosing one's attitude maybe dignified but it is idealistic when societal attitudes powerfully affect the way people with dementia view themselves and their ability to do things. According to its biomedical meaning, Alzheimer's disease, which is but one cause of dementia, is a degenerative organic disorder of the brain (Faull, 2007), yet living with the symptoms of Alzheimer's disease invariably means living with two diseases; one social and one organic (MacRae, 2007).

Living with dementia

A person's being in the world does not stop with a diagnosis of dementia, yet their ways of living are changed forever. Heidegger (cited in Kögler, 1999) called on us to understand Being in connection with all the dimensions of temporality – past, present, and future. What reveals itself to us in the present is shaped by the past and the future, whether this is obvious or not. Therefore Being includes absence as well as presence. So Being is not merely a chance state; our 'Being-in-the-world' is influenced by all that has gone before, and based on this, our future anticipations. This suggests that people's experience of living with dementia is shaped by their previous values and attitudes, and their future hopes and dreams. To explore this notion I needed to understand people's way of being in the world prior to the diagnosis of dementia, because those ways of being will shape how dementia influences their life world.

Ways of being prior to a diagnosis of dementia

People's way of being earlier in their life world shapes their attitudes to the changes brought by the onset of dementia. For Scott, the idea of dementia was anathema, an assault on his personal self-image. Although he and his wife Polly, have been married for 38 years

they virtually lived separate lives. Originally from Britain, Scott spent many years in the Merchant Navy, working his way up through the ranks to become a Deck Officer. He enjoyed the lifestyle and on leaving the Navy Scott, who is a qualified Foreign-Going Master, became a sea pilot responsible for guiding ocean-going vessels into port. Routines were important to Scott: *“Being on the ships where we have routines, that sticks.”* When asked about his routine nowadays, when he is at home, alone he talked enthusiastically about getting his breakfast, reading the paper, and doing the crossword *“even if it takes all day.”*

I’ve got a fairly normal routine and, em, I’m quite happy sitting, just footering around. I take the dog out and do all that stuff. I em just try to keep busy. I don’t, eh, just sort of blob, I would say that 80% of the time I’m doing something. Polly makes sure that I do all that stuff so let’s leave it at that.

Scott previously worked long hours. He had a position of authority, was confident, used to being in control, and he took pride in being independent: *“Since the time I went to sea I’ve never needed anyone, I’ve looked after myself.”* Insisting he was active during the day helped Scott to preserve his self image, since participation in daily activities provides a sense of normality and gives structure to the day. Being unable to engage in his usual occupations undermined his self confidence and deprived him of his sense of autonomy so even though he seemed to accept his cognitive decline, Scott did not allow thoughts of ill health to invade his sense of self. In reply to the greeting *How are you?* he would always respond *“Physically I am well.”* Nonetheless, Scott’s positive outlook was belied by his posture. Invariably his stance was slouched, shoulders drooping, hands in his pockets, and he scuffed his feet when he walked.

To further illustrate the role earlier life plays in an individual’s attitude to cognitive decline, Rita, another of the participants, had been a competent wife, mother, and homemaker. Married to Bernard for over 50 years, they seemed to have a good relationship. Rita was a gifted singer with a passion for musical comedy. According to Bernard, music has always been important in their lives and indeed, he said it brought them together. Bernard is a skilled pianist, Rita plays the guitar, and each one of their five daughters plays a different musical instrument. As a family they used to entertain at concert parties in small theatres and rural halls around the country. Being a confident, outgoing person with a zest for living, Rita talked positively about dementia. In her opinion, having dementia has not made

any difference to her being in the world. On the contrary, Bernard said Rita's cognitive decline really became evident when doing household tasks:

She would start to make a meal, then go off and do something else and forget all about the food cooking on the stove, or she would neglect to vacuum whole sections of the carpet, and put things away in unusual places.

In conversation, Rita stated that they usually share the house chores but Bernard reminded her they have a caregiver who comes once a week to help because they can no longer cope. According to Bernard, who has his own health problems: *"I do the majority of the work."* Bernard said taking over the daily household tasks was a gradual process, and Rita seemed oblivious to the fact that it was happening rather she maintained an image of herself as competent and socially accomplished.

Heidegger tells us that ways of being are evident in various ways. They may be revealed through something that shows itself but is not the actual thing in itself. This is referred to as an 'appearance' (Kögler, 1999). In Rita's case the decline in her functional ability is the appearance of Alzheimer's disease. The change in her ability to do daily tasks subtly became apparent and although the appearance was gradual, Bernard slowly came to think that something was wrong; he just did not know what that something was. According to Kitwood & Bredin, (1992), this is consistent with the onset of Alzheimer's disease inasmuch as problems are usually identified by others. The person with the problem may be unaware their behaviour is different.

Becoming different

Bernard said he was conscious of a difference in Rita for some time before he actually said anything to her because he had concerns about voicing his thoughts:

I didn't want to offend and basically in my own mind I thought what do I do about this? ... I didn't know how to approach it because she'll be highly offended and then I just came out with it one day, didn't I? You took it reasonably calmly ... you said "Well I don't think so," you said "but if you think so, we'll go and see the GP" ... she [GP] did some simple tests ... some memory tests and sent you on to Older People's Health at Auckland Hospital.

Rita refused to be perturbed by the knowledge that her way of being in the world was changing. Even though problems were manifest in her declining practical abilities, Rita was

still functioning in her world well enough to maintain a relatively normal lifestyle and to interact with others in a socially appropriate way.

Gran and her husband Pop's experience of the onset of dementia provides insight into psychiatric changes in personality that led to a diagnosis of Alzheimer's disease. Gran and Pop have been married for over 40 years. They have three children of their own and cared for three other children who needed a home. Although Gran had a variety of jobs in the community throughout her married life, she mainly worked as a cook. She took great pride in keeping the family home and garden clean and tidy. These days, Gran admits *"I've slowed down a lot, I'm not as fussy as I was"* but that may well be due to the fact that she also has osteoporosis and uses a walker to mobilize. Gran now receives assistance with personal activities of daily living from social services as she has a caregiver who comes in for one hour each morning, Monday to Friday, to help her shower. Another caregiver comes once a week for two hours to assist with house chores. Accepting this help means Gran has more time to do the things she wants to do. For instance, Gran took great satisfaction in telling me: *"I still do all my own cooking."*

According to Pop, his previously happy life with Gran became *"hell"* as a result of paranoia which went on for a long time before she was diagnosed with Alzheimer's disease in 2003. Both were aged 61 at the time and it was a huge relief to Pop to have an explanation for Gran's unpredictable behaviour and unfounded accusations:

It was terrible, just horrible, even getting out of bed and going to the toilet I'd come back and oh yep "You've been out somewhere ...you've been to visit someone." Just because I'd go to the toilet and come back, "who've you been visiting?" and stuff like that.

Pop did not know what was wrong with Gran. In looking for help he said: *"I was crying to the doctors, I went to the clergy, never been to church in my life but I went there"* and no one was able to offer an answer. Pop said he was pleading *"You don't know how hard I was pleading"* and literally broke down in the doctor's office. As a result, the GP decided he was suffering from depression. Pop's response to this was:

I've got depression alright, I do feel depression... I know exactly what it's like I can tell you what it is like... I used to go to work and I was afraid to come home because "Where have you been today? What have you been doing? Who have you been with today?"

For her part, Gran said she has no clear memory of being paranoiac. She assumed that the uncertainty of what was happening made her fearful and suspicious: *“I couldn’t think.”* Since being diagnosed with Alzheimer’s disease this has changed, and Gran said she no longer has the same fears. Her attitude is one of acceptance while Pop said it was a relief to actually get the diagnosis. Drawing on the work of Heidegger, Gadamer (cited in Kögler, 1999) stated that “to understand the meaning or subject matter under discussion, a general understanding of being must always already be brought into play” (p. 58). Gadamer’s concept of a fusion of horizons is a metaphor which informs our understandings.

Gadamer (1976) claimed that behind competing interpretations is a shared reality – a world, a tradition, a language. If the reality is familiar, we can anticipate a ‘fusion of horizons’ when people enter into dialogue on a common subject matter. Further, he argued that history is not an external entity from which we are removed; rather it is an evolving process that constantly embraces us. Denying that this necessarily leads to relativism, he proposed that the fusion of horizons that takes place in understanding is language’s greatest triumph (Gadamer, 1976). “Understanding is always the fusion of these horizons supposedly existing by themselves” (Gadamer, 1993, p. 306). For those who are open to learning in this way, understandings continue to grow. Even more, enhanced understanding then becomes a platform for action.

Reconciling Gran’s behaviour with the knowledge gained through diagnosis enabled Pop to ‘see’ the behaviour in a new light and thereby put it into context. Between them, Gran and Pop said the day they got the diagnosis: *“We came home...we had a cry, both together...hugged each other and now what are we going to do?”* They agreed that *“positive thinking”* was the way ahead. However, other participants did not experience the diagnosis of dementia with the same relief.

Being diagnosed

A number of participants referred to the way in which they were given a diagnosis of probable Alzheimer’s disease. Rita was told she had Alzheimer’s disease by a psycho-geriatrician in 2005 when she was aged 74, and Bernard was 78. According to Bernard, the way in which the specialist revealed his diagnosis was very unpleasant:

We went to a specific area at Green Lane where they deal with dementia people and ...they did a scan ... and then [the specialist] came back from that and said to Rita

quite bluntly: “You’ve got Alzheimer’s, now does that worry you?” and I thought to myself well, I wouldn’t like to be told like this.

To add insult to injury, once he had given the diagnosis the specialist then went on to exclude Rita from the conversation and confer with Bernard:

Bernard: *He struck the wrong note because he kept asking me questions.*

Rita: *I was infuriated he was ignoring me and speaking to Bernard and I was livid.*

Bernard: *When he went out of the room she said to me “I’m so mad I’m going to speak to him” and afterwards I told him.*

Rita: *At the time I thought well, this is just going a bit too far. If it’s my problem then I should be able to speak about it.*

Overwhelmingly framed as an organic brain disorder, treatment of people with dementia has, to date, been carried out within a narrow paradigm (Banerjee, 2005; MacRae, 2007; Sabat, 2001). Within this paradigm it is very easy to disempower people and make decisions on their behalf, because it is assumed that their cognitive and communicative skills are impaired. In taking umbrage with the specialist, Rita was proclaiming her right to maintain her identity as a competent human being capable of entering into dialogue for herself.

Dissatisfaction with the delivery of the diagnosis was not confined to Rita and Bernard; other participants had similar experiences. Scott was another participant who spoke of his “*very bad memories*” of being diagnosed with Alzheimer’s disease. Scott said he knew “*things were happening*” but nonetheless the actual diagnosis came as a tremendous shock:

Scott: *The worst experience of this ... I had an ECG an’ what’s the other thing they give you?*

Grace: *An MRI scan?*

Scott: *Yeah, I had a scan and what’s these tubes?*

Grace: *Neuroimaging?*

Scott: *Yeah I had all of that and ... I don’t know what happened that day. I didn’t feel that the doctor helped me at all. Once you get into one of these places they tend to just say sit down and they’ll get to you when they are ready sort of thing. I just wish some somebody had stepped in somehow...instead of a stranger.*

In addition to a sense of desolation, Scott felt he had received little or no support from hospital staff. The diagnosis was clearly distressing and in reflection, Scott said he found the assessment process “*scary*” and the professional approach “*insensitive.*”

Becoming dependent

During discussions Scott was reluctant to acknowledge changes in his way of being and insisted that he was untroubled by the disease: *"I've got Alzheimer's and that is something I've just got to deal with. I'm aware of that an' I'm just gonna take it one day at a time and so far it's nothing."* In saying that, he did not recognize his increasing dependence on Polly. Knowing Polly prepared lunch before going to work, I suggested she should perhaps leave Scott to prepare his own lunch. However, Polly was concerned that if she did not leave something, Scott would go through the whole day with nothing to eat. Since Polly had expressed concerns about his obvious weight loss (down from 76kgs to 65kgs in less than six months), I asked Scott about preparing food for himself during the day. He was adamant he could look after himself but admitted: *"Polly usually makes me a packed lunch an' she's left that."* At 11.30am, the packed lunch in question was gone from the kitchen bench where Polly had told me to look for it. The following conversation followed a suggestion that he prepare a sandwich for lunch before I left:

Grace: *How about you make yourself a sandwich now before I leave because I know Polly is concerned that you are not eating and drinking enough during the day.*

Scott: *I've been grazing all morning.*

Grace: *What have you had?*

Scott: *I actually make sandwiches myself regularly...I'd get the Vogens the margarine, or butter or stuff, yoghurt and do all that stuff, get the lettuce.*

Grace: *I'm wondering how you would cope if she left it for you to do?*

Scott: *Of course I could. It's just that she does it...if she hadn't made sandwiches for me I would have made it myself. It's that simple.*

Grace: *Do you ever go out with friends for lunch?*

Scott: *I don't have many friends.*

Scott's argument that he could make himself a sandwich was not put to the test because I was not inclined to show my scepticism. Although I doubted his ability, I did not want to upset his self-image by forcing the issue and possibly embarrassing him. However, on the next visit I took along sticky buns for morning tea. Scott was visibly pleased about this and so I suggested he make coffee to go with them. He readily agreed but on going into the kitchen he hesitated before saying: *"I hope I can find things in here."* Scott was slow to gather the required items and needed prompts and cues to get the coffee made. For example, after searching various cupboards and finding a coffee mug, coffee, sugar, and milk, one item at a time, he stopped as if the job was done. I had to remind him to put the kettle on. Having made one cup of coffee, I then had to prompt him to make another one for himself.

Scott did not appear perturbed by this inefficient use of time and energy. He went through the whole process again, sometimes requiring a prompt and still one step at a time. It was very apparent he enjoyed *“Having someone to chat to.”* In conversation over the coffee I asked Scott: *“How do you cope when you can’t do things you want to do?”* He replied:

That’s a tricky question. Well if I get to a point where I can’t do something I need to do I would get around it some other way. Deal with it or just give it away... if it’s too hard. ... If there’s something I couldn’t handle I’d get someone else to do it. It’s as simple as that.

Functional ability is important to a person’s sense of dignity and self-respect yet for a person with dementia everyday activities, taken-for-granted by most of us, become challenging. Even familiar practices are lost when the memory of how to ‘do’ them is impaired. Literature shows that this loss of ability impacts on the person’s self-confidence and self-respect (McRae, 2007). I believe Scott wanted to maintain his self-respect and dignity by insisting he is unaware of any major problems, and I eventually came to think that this may be a way of coping with the diagnosis and all that it entails. This not only applied to Scott. Polly had previously said that by *“Going off to work I can put my mind to other things and not think about things too deeply.”*

Living a dignified life

The notion of dignity and respect is receiving more recognition in ethical debate around the world. In fact, the right to dignity is a key feature of the United Nations Standard Rules for the Equalisation of Opportunities for People with a Disability (United Nations General Assembly, 1993). Governments are being called on to ensure that all disabled people have the opportunity to live a dignified life regardless of the type of disability. Similarly the WHO recognizes the relationship between self-respect and health and many of its strategy documents have addressed this issue. For example, the International Classification of Functioning, Disability and Health (ICF) (2001) acknowledged the multifaceted nature of health inasmuch as the constituents of health are described from the perspective of the body, the individual, and society. Although personal factors such as dignity and respect are not classified in the ICF, they are recognized as playing a part in health-related states. Thus the ICF shifts the focus to life, how people live with a chronic health condition and how it can be managed to achieve a productive, fulfilling life.

According to Kögler (1999), such questions heed the conditions of language and culture as well as the everyday values and attitudes that influence human existence. Nobody is fully aware of that which makes a person. We are not simply a product of our genes. The socialization processes to which we are exposed and through which we gain access to a world of meaning and traditions are equally important. These influences, which become embodied, both open up and limit our horizons (Gadamer, 1993). Thus, it is only through them that we have horizons and are able to encounter ‘things’ that extend our horizons (Dutt, 2001). This is essential to “make possible a critical understanding that goes beyond and gets behind oneself and our own norms” (Kögler, 1999, p. 109). In other words, in trying to understand what it means to live with dementia it is our own interpretation of what it means to others that we will understand. Understanding is always dependent on our own interpretation of understanding the other. ‘Other’ includes people (their attitudes and behaviours) and/or the writings of an-other as in text (Gadamer, 1976).

Other people’s perception of what it means to live with dementia is a composite of all the positive and negative information they have acquired. Such knowledge takes on new meanings, both accurate and inaccurate, with the ongoing accumulation of understandings. In other words, the effects of dementia can be reduced or aggravated, depending on how the person is treated by others in the everyday world. In considering the nature of social interactions we come to understand that others can have positive and/or negative effects on the subjective experience of the person with dementia. For instance, the degree to which they can display intact cognitive abilities, their ability to meet the demands of everyday life, the quality of the person’s social life all influence the meaning found in every day (Sabat, 2008).

Being active

One manifestation of living life with dignity is to be with people who are inclusive. Dutch and Moses live a full and active life doing things they have done for over 30 years. Dutch, who was diagnosed with Alzheimer’s disease in 2002, aged 67 said: “*It was a shock, it was a big shock, but it doesn’t worry me now... well because I can’t do a thing about it.*” At the time Moses said he was the more devastated of the two: “*I think the shock for me was greater than it was for Dutch. All I knew about dementia was what I had heard about my grandfathers who both had dementia.*” In coming to terms with the diagnosis, Dutch and

Moses agreed to continue living life to the best of their ability for as long as they could. To that end they eat a healthy diet and keep active. Rather than allow Dutch to become a helpless and confused person lacking a sense of being in the world, Moses encouraged him to offset the debilitating symptoms of dementia by engaging in routine daily activities:

Moses: *We go out playing table games three mornings a week.*

Grace: *Sounds good, where do you do that?*

Moses: *At the Mt Roskill Community Centre is two days and the Epsom Community Centre is one day.*

Grace: *Do you enjoy that, Dutch?*

Dutch: *Yes, Mahjong Mahjong and eh*

Moses: *The other one is called Rummikub*

Dutch: *Yes, Rummikub*

Furthermore, they are members of a Classical Music Club, a Couples Club, and the Fruit Season Garden Club. Moses said: *"We've joined the Auckland Music Club... we go off there I think it's every third Tuesday of the month... and we thoroughly enjoy that."* They go out walking daily and until recently they travelled overseas at least once a year, but last year they had to cancel a trip because Dutch was put off by the thought of all that travelling entails. He said *"I especially hate the hustle and bustle of airports."* So they went for a sea cruise instead. Moses' rationale was that at least on a boat Dutch would not get lost.

One of the wonderful aspects of the relationship between Dutch and Moses is the way they talk things through. Moses said: *"I always confer with Dutch and we make decisions together."* The extent to which the person's independence and well-being can be maintained has profound effects upon the degree to which that person can interact on a day-to-day basis in the social world. Dysfunctional social interactions change social connections. Equally, according to Banerjee (2005), the ways in which a person with dementia is treated will in turn affect the way in which that person behaves.

For the partners of people with dementia, dealing with declining abilities in their loved one can become all consuming. For instance, after Rita was diagnosed with Alzheimer's, Bernard tried to learn as much as he could about the disease process. He was determined to help Rita find ways to offset the symptoms. Bernard is vehemently opposed to the idea of Rita being put into a rest home should something happen to him, so his goal is to help her retain cognitive abilities so that she remains in her home. Bernard uses cognitive

stimulation therapy to challenge her on a daily basis because he believes that making her brain work will help to stimulate the brain cells. He *“pushes the memory on every little detail.”* For example, they start each day with a walk, and while walking, Bernard will ask questions like: *“What was the weather like yesterday? Who did we meet? What colour hat was she wearing?”* In addition, they routinely do mentally-stimulating exercises like Sudoku puzzles.

Rita has absolute confidence in Bernard and is quick to acknowledge him as her greatest ally. She considers herself very lucky to have such tremendous support:

You see I'm a very fortunate person because of Bernard's attitude. You see he certainly does help me... if he can see that I'm sort of retiring and going into myself he'll talk [about] it. Even though I'm mad, you know, if I'm cross he'll say let's talk it out. So he is a help, a tremendous help.

Rita and Bernard lead a full and active life with routines that include a combination of physical, mental and social activities. In this way they strive to offset the progression of dementia. Bernard, who claims to be impatient by nature, voiced two major concerns related to caring for Rita. The first:

I will not always have the patience required to support Rita. Look I'm nagging constantly, constantly, constantly to concentrate. If she asks me a question I say I'm not answering, now concentrate. I mean I find it hard myself it's such a pain because it must be awful to be told all the time about ordinary things - concentrate. But I don't think there's another way. I don't think there is a possible way around Alzheimer's.

Rita: *What it does for me is I find yes I've got to remember. It's like a positive injection if you like. I know that what he is doing is trying to help.*

Bernard: *I constantly fear that it will get too much for my sanity. It's very hard to get used to...it's almost impossible when I've just asked you to do something and you've done something else. Being humorous at a time like that is important but it's damn near impossible. I'm constantly praying that I will be a support.*

Bernard's second concern was greeted with laughter: *“I do all the cooking.”* In response Rita said: *“But you do it so well”* at which point I suggested: *“Sounds like that's more by design than dementia.”* It is distinctly possible that after 50 years of cooking, Rita is happy to relinquish that task to Bernard. A decrease in functional ability may not be determined solely by the disease process. A contributing factor may be aligned to the fact that in older age many people let go of activities they no longer enjoy (Cox, 2005).

Being and becoming

However challenging the process of dementia may be, the decrease in a person's ability to do things is not total. One of the hallmarks of cognitive decline is a decreased ability to participate in daily activities, yet people with dementia are actually able to respond to the world and to communicate through engagement in daily activities until very late in the process (Sabat, 2008). As the following dialogue will show, variability in terms of personal characteristics, histories, the pathological process, and the quality of social relationships, as well as pre-morbid abilities, influence the things people with dementia do during the day. Extending Gadamer's concept of understanding as a fusion of horizons, Kögler (1999) argued that "either we understand something as true within the fusion of horizons or we explain it through contextual circumstances" (p. 140). The following report on daily activities puts the day-to-day life of two sets of participants into context. A fusion of horizons is found in their relationship, in understanding what is important to the other. The consequences could be very different without a supportive partner.

When I first met Rita there were no obvious signs of dementia. She knew her memory was poor but she stated: *"At the present time I think I am, quite seriously, I'm coping."* She acknowledged that she did not do as much as she used to around the house but on more than one occasion she was observed efficiently making refreshments after our discussions. Rita and Bernard are active in the community, routinely visiting Rita's mother who lives in a rest home, and socializing with their children and grandchildren. They also go to the theatre, the cinema, or out to lunch at least once a week. The following flow of dialogue reveals the pleasure they get from doing activities they enjoy. It also reveals Rita's awareness of the importance of daily activities:

Rita: *Yes, I have this disability. You know, the memory at times ... Alzheimer's I have digested that, I have looked at that and I have faced it, but I feel that so far I'm doing okay because I've got an understanding husband and we do not sit at home. This is where I think I'd eventually ... if I had to be staying here all the time, I could see myself just going downhill with nothing to do.*

Bernard: *We go to the University season when it's here, once a week in town. The College of Music at the University, they have it every Friday.*

Rita: *Every Friday, really lovely, very good cast.*

Bernard: *We get on the train to get into town, then we have lunch somewhere, and there's a free bus to the University. Gosh last time we went it was a*

Rita: *Marvellous, marvellous day.*

Bernard: *We both love our music. The whole family loves music so this was fantastic. It's a real social event for us, it's important to us.*

Rita: *Oh! It's important to me yes, because it's an outing you know. I like getting on the train.*

Bernard: *Yes, we've got our favourite seat.*

Rita: *I mean there's nothing to it. It's very simple but I think all those things help.*

Bernard: *It's wonderful. You get in among the university students, which is an education in itself.*

Rita: *The standards are remarkable*

Bernard: *Beautiful singing and, we've even picked out a favourite seat in the theatre.*

Rita: *I tell you straight, I would be a very different person...I'd be far more difficult wouldn't I?*

Laughter

Rita: *No, no, I'd go within myself.*

In addition to the pleasure derived from engaging in activities, Rita believes maintaining a balanced lifestyle while living with dementia is important because participation in daily activities helps her to “*maintain confidence in myself.*” Interestingly, Rita is so confident that, following one of the focus groups in which a number of participants came together for the first time, other people thought it was Bernard who had dementia because he sat quietly while Rita did the talking. Even so, Rita admitted that loss of confidence is one of the more debilitating factors she has to deal with: “*I do know that I don't feel as confident because I realise I have this Alzheimer's.*” She was aware that a change in her level of confidence is undermining her abilities:

With a reasonably big family over the years and running the family well and coping with all sorts of situations and then all of a sudden...it's a feeling you get that oh perhaps I'm not so good any more in sorting this or that out. I will sort of step back and think oh no perhaps I shouldn't. It's the loss of confidence.

Nonetheless, Rita strives to retain control of her life. To all intents and purposes she goes on, not avoiding the fact that she has dementia but living in the present with Bernard's support. Her life continues as before by understanding, adapting, and revising occupations. The ICF defines the notion of occupation as a combination of activity and participation. Apart from the social determinants of occupation that originate in environmental factors, many personal factors also influence occupations or the things people do. Lack of opportunities to do things may, of itself, lead to a poor sense of well-being but equally the right kind of doing is considered a prerequisite to health (Wilcock, 2003).

Gran was another participant who refused to believe she was disabled. Rather than underestimate her abilities, she insisted her life had not changed: “*No, not really, not*

really.” Gran’s approach to enjoying life is reflected in her involvement in the country music scene:

I’ve been on all the committees, I know what goes on. Out at country music just about every night I was. I’d start on a Sunday Manurewa, Tuesday’s Papakura, then I’d be Wednesday, where’d I go Wednesday? Thursday Franklin or Tuakau, Waiuku on a Monday night and every second Sunday is Manurewa now. It used to be every Sunday but every Tuesday’s Papakura. Now I go twice [a week]...

There were times when it was apparent that Gran lacked insight into the effects of having Alzheimer’s disease. For instance, she insisted: “*I gotta be independent, I am independent*”, revealing that while her positive attitude supports her self-image, in reality it is inaccurate because she is no longer driving and so Pop takes her wherever she wants to go.

As well as going to country music clubs two nights a week, Gran has regular activities which take her out four days a week. “*On Tuesdays and Wednesdays I go to Selwyn Homestead in Papakura.*” There she attends the day-care centre where she spends the morning participating in a variety of physical, mental and social activities. After lunch a van picks everyone up and takes them home. “*On Thursdays I have my hair done before going to play cards with friends for the afternoon and on Friday mornings I go to Housie at the Papakura Bowling Club.*” When Pop teased that she never wins a big pot, Gran replied: “*The crowd is not very big but it’s good, it’s friendly. That’s what I like about it, it get’s me out.*” At home she keeps a book of word games handy because she believes it is important to keep her brain active. According to Pop, Gran is a very determined woman. This was confirmed when she said:

I’m determined that I’m not going to stop doing things. And anyway you’ve got to do something. I feel if you let it go it’s just going to get worse and I’m determined I’m not going to let that happen. I still go to my country music. If there’s a concert on I still go to that and I’m determined I’m going to keep going to go as long as I can.

Having been a member of the Papakura club for over 25 years, Gran is due to receive honorary membership: “*I’ll hang in for that.*” Receiving that life membership is obviously meaningful to Gran and encourages her to maintain regular attendance. Thus, constructive support, positive attitudes, and social interaction contribute to health and well-being. When people are deprived of opportunities for occupational and social connectedness they have

less protection from declining abilities (Banerjee, 2005; Dabbs, 1999; Kitwood, 1997; Sabat, 2003).

Becoming less active

Greg was 62 years old when diagnosed with young onset Alzheimer's disease in 2001, following several years of declining abilities. His wife said he refused to accept the diagnosis or even talk about it for quite some time. The diagnosis was later changed to one of Lewy Bodies Disease due to the multiplicity of symptoms.

Greg referred to his cognitive deficits as "*brain fade*" thus suggesting that he has difficulty sustaining concentration for any length of time: "*Sometimes I don't feel like doing anything and I think at the end of the day – what a waste of a day.*" In terms of living with dementia he said: "*I think the hardest thing is being unable to do things...time hangs heavy on your hands...because I can't do the things I normally do.*" A builder by trade Greg, who had his own business, previously enjoyed physical activity. He liked to do odd jobs around the house but the Parkinsonian-type symptoms that are a component of Lewy Bodies disease impeded his ability to do things:

If I try to do things around here, which is what I wanted to do when I retired, maintenance...I get very tired very quickly...and if I actually push myself too hard I end up with this (showing an intense tremor in his hands) going like mad.

Greg was inclined to distance himself from the idea of needing help: "*My needs are not great at this stage.*" He did not like the idea of asking for help from others. What is missing here "is the necessity of self-distanciation [sic] in making possible a critical understanding that goes beyond and gets behind ourself and our own norms" (Kögler, 1999, p. 109). In other words, if Greg had been able to stand back and look at his situation objectively, he might see that by refusing to ask for help from others he is actually compounding his problem. Alternatively, if he accepted the need for help he may have more opportunities to be active.

Previously, social activities were very much a part of Greg and Fiona's life, yet they both acknowledge they no longer try to keep in touch with friends or the various people who used to frequent their life. Despite having been a passionate sailor, Greg no longer goes to

the yacht club where he was a member for over 25 years. For various reasons, people who were once important to them have gone from their life:

Greg: *Our circle of friends has changed quite dramatically, quite dramatically.*

Grace: *I think that happens in the normal run of life.*

Greg: *Some of them are no longer there, gone in different directions.*

Fiona: *They do, they get taken up with different jobs, or a lot of them have retired.*

Greg: *We used to belong to a sailing club, our whole social life generated around that group of people. Then after a while you go down there, and there'd be less and less people we knew till at some stage, we'd go down there and look around the room and I don't know anybody. You know, I lead an active part in this club and there's nobody here that I know.*

Fiona: *We had a place up at Kawau, and we used to have a lot of friends who'd come up there and stay for the weekend. Then, I can't come this weekend. I've got the grandchildren or, I can't come this weekend you know 'cause we've got to leave the animals or the kids have got something on this weekend and I've got to be there. We were finding more and more too weren't we Greg, just as our children age so things change in your life. You go in different directions; it's just what you do.*

Grace: *It happens.*

Fiona: *Yeah, I think we both thought we'd be employed, or at least be doing something we enjoyed at this age. We never anticipated something like this happening to either of us.*

Greg: *No, I had no intention of retiring. Slowing down maybe but not retiring.*

According to Fiona, Greg is “*living a fairly aimless life in some respects.*” In reality, he has no alternative. The local Alzheimer's Association runs a ‘Blokes Group’ which meets once a month and of this Greg said: “*We do activities that we look forward to incredibly. We're all in the same boat ... and we have a lot of fun.*” He also attends another group meeting run by the Parkinson's Society every three months for “*a chinwag followed by a small lunch.*” However, these activities are not enough to prevent Greg from becoming socially isolated.

Existing in social isolation

Social isolation is repeatedly reported as a key concern of people with dementia (Dabbs, 1999; Reid, Ryan, & Enderby, 2001). How a person with dementia is perceived and referred to by others may make them vulnerable to losing social connectedness. Following diagnosis, Scott said going back to work was out of the question: “*I just stopped ...I said, I'm not coming back to work for a while.*” Although he did return to work briefly, in the end he took early retirement because: “*Nobody helped me...that's the culture down there.*” On reflection Scott added “*Well there's certain people who helped but...*” Scott seemed to have felt cut off from his co-workers and although he never spoke of the experience,

according to Polly, when it was revealed during discussion his sense of distress was obvious.

In response to a question about daily activities, Scott would talk enthusiastically about getting his breakfast, reading the paper, and doing the crossword “*Even if it takes all day.*” When asked about social contacts, he said he didn’t have many. I asked about going out and about but he assured me he was quite happy on his own. This is a man who previously worked 10, sometimes 12, hours a day. This is a man who tells his wife when she comes home “*It’s been a looong day.*”

Lack of transport is a contributing factor to social isolation. When people lose the right to drive following a diagnosis of dementia, their sense of isolation is compounded by the loss of independence and control. Greg identified this in response to a question on the support needs of people with dementia:

Grace, about help in terms of this research, for me there’s probably not a great deal because I’m lucky Fiona’s not working and eh while I’ve lost the privilege of being able to drive, she can drive me around. But a lot of them as Fiona’s mentioned before, the wife or spouse goes to work and leaves the other one at home and if he’s not driving ... That’s where there probably needs to be effort put into how can we accommodate those people ... cause it’s a long day on your own.

Although Greg did not acknowledge his own transport problems, in reality Fiona sustained a major back injury which causes her significant pain and limits the amount of driving she can do. After several years of rehabilitation she maintains a rigorous therapeutic regime. In addition, Fiona engages in a variety of personal activities and she is firm in her commitment to them. Consequently, transport opportunities for Greg are limited.

In response to Greg’s comment, Fiona identified a common need for people with dementia, particularly younger men, to have opportunities for a productive and meaningful life. With regard to this suggestion, I referred to a role Greg undertook as a volunteer during the run up to the America’s Cup race in 2000:

I was just thinking of something, I think a lot of ... you guys or the guys in your group [young onset group] are ... living a fairly aimless life in some respects. They need a project; something that they can see is evolving, that maybe at some stage becomes completed. I don’t know what sort of a project, but you could see the point in that couldn’t you?

Grace: It’s about having a purpose in life.

Fiona: *Yes, and it's about having a finish date and ... then start something different, so that is perhaps I think what Greg needs.*

Grace: *What do you think Greg?*

Greg: *Some sort of hobby?*

Grace: *I think you mean more than a hobby?*

Fiona: *It's a project. See, when you were building a house you went through all the steps of it from ... doing the plans to the finished article. There's something very rewarding about doing something even if it's simplistic or a joint project.*

Grace: *Like the America's cup?*

Fiona: *That was a project.*

Greg: *That certainly filled my time in for a couple of months, something every day.*

Fiona: *It was really, really good for you, and you had all that interaction with other people. People you wouldn't normally meet.*

Grace: *So, ... what you're saying Fiona is to have an opportunity... to use skills and abilities to a purposeful end. Is that what you mean?*

Fiona: *Yes, something like that. I mean I know often they've got handicapped people or troubled people, troubled youth, often they've painted murals on walls or they've created something or, they've just simply got together as a group ... everyone's got a different skill level, and often people have special abilities.*

Mick was another participant who lived a solitary life five days a week. Diagnosed with young onset dementia, Mick liked to spend time with his wife of 35 years Marianne, and their two children. An easy-going person, Mick was a qualified engineer who said he liked helping other people. When I asked how he spends his time when Marianne is at work, Mick responded:

I think I'm good at doing nothing, I mean the day just goes. I potter around here

Grace: *What would you like to do?*

Mick: *I don't know. Job-wise or what?*

Grace: *About keeping active during the day.*

Mick: *One thing I do find is that I get irritable.*

Grace: *Where or when do you get irritable?*

Mick: *At home 'cause I can't get something right, I get frustrated and it annoys me.*

Mick's frustration is understandable when traced back to his previous abilities. Practical ability is an essential factor that affects the use of objects. Equally, the use of objects is a crucial factor when performing daily tasks. Yet the ability to use objects in a functional way makes complex demands on cognitive functions. Since much of what people do during the day gives purpose and meaning to life, it is easy to understand Mick's irritation at the loss of ability to use objects. Purposeful activities are important because the act of doing enables people to feel useful and connected. Declining communication skills was another problem that detracted from Mick's ability to socialise.

Encountering communication deficits

Communicating is something we take for granted, but in reality it is a complex process. It relies on our ability to listen, process the information and then form a response based on our understanding of what we have seen or heard (Sabat, 2001). For some people with dementia, communication can become increasingly disrupted and impaired yet communication skills are an essential aspect of social interactions. From this point of view, when the ability to communicate with others is endangered, interaction with people becomes challenging (Widdershoven & Berghmans, 2006). Mick could register and process information, but he was sometimes slow to respond and/or would lose his train of thought during a conversation. Occasionally he had word-finding problems, would mispronounce words and there were times when his sentence structure was poor. Yet despite these problems, Mick was able to communicate a great deal about his experience of living with dementia. For instance, he explained why communication deficits make him feel inferior to other people:

Sometimes your movements are clumsy or you lose confidence because you try to do things or say something but get muddled. The words get jumbled, and so you give up. Your thoughts are slow and you can't keep up with the conversation.

Marianne reported that Mick was increasingly reluctant to mix with other people and so friendships waned:

Marianne: We've known this couple...for years but he's a very outspoken person, he always has been, those things don't change. He makes Mick feel inadequate and it's really spoilt our friendship. He is so overpowering...you don't get a word in edgeways.

Mick: I hate going out.

It is not surprising that people with language deficits become isolated from others. According to Sabat (2001), going “from a competent level of communication to an uncertain level, must inevitably lead to a sense of dissatisfaction, annoyance, impatience, anxiety, and low self esteem to the point whereby a person may refuse to speak in other social situations” (p. 69). Greg confirmed some of these points when he stated:

I find it not easy...conscious of the trouble I have with my voice and from time to time I miss a word or I go to say a word and it disappears completely out of my head so that in itself builds a lot of tension in me...makes socializing very difficult.

Scott is also affected by a declining ability to communicate. His sentences are often interrupted by lengthy pauses. Parentheses have been used to show the pauses occurring in one sentence to give some sense of the pace of his speech: “*The problem is [pause] with me [pause] is probably I [pause] yeah I’ve got a real stuttering in my speech and it’s [pause] but I get there.*” The duration of the pauses, does not determine the success or failure of the conversation. The success of conversations with people with dementia depends on allowing them time to frame their thoughts (Sabat, 2001). Scott communicated effectively despite his ‘stutter’ and he offered some profoundly meaningful information to this study. His tone of voice was definite and the meaning of his sentences was more often than not quite clear. He had little difficulty in a conversation with one other person but he said when he is company the conversation moves too fast and he cannot keep up. Finding words was also difficult at times. Time and patience are required when engaging in conversation with a person with declining communication skills. This is endorsed by Sabat (2001), who advocated that understanding can be achieved by being patient and not putting words in the gaps, rather waiting and listening for meaning and tuning into tone of voice.

Gadamer agreed with Heidegger’s claim that “language and understanding are inseparable structural aspects of human being-in-the-world” (cited in Linge, 1976, p. xxix). The being of language is in its power to express meaning. Words and subject matter, language and reality, cannot be separated so understanding is reliant on the extent of our common language. Thus, language is both the medium and the product of society which allows being to come into words. According to Gadamer (1976), it is on this level that language emerges as the universal medium of understanding. Furthermore, Gadamer (cited in Linge, 1976) argued that “what is disclosed in language poses ever new questions to its interpreter and gives new answers to those who are challenged by it” (p. xxxiii). Language, both verbal and non verbal, is the basis of communication and through dialogical interaction, new understandings enabled a number of actions in the course of this research.

Action at participant level

Early in the process of data collection, the cyclical process of observations and reflection played an essential part in both my and the participants’ knowledge development. In other words, identifying a problem, reflecting on it, taking action, then reflecting again before offering a critical interpretation was an opportunity to realise that truth and meaning

involve interactions between interpreter, the participants, and their sociohistorical contexts. With regard to engagement in daily activities, various participants revealed problems they encountered, and the issues arising captured my interest. Sharing knowledge was both disclosive and productive because the dialogue led to various courses of action which are outlined in the following discussion. This is in keeping with Kemmis' (2010b) call to focus on the happening-ness of action and practice.

The first practical opportunity for action on my part came after talking to Scott. I came to realise the questions I was asking were inappropriate because I was looking for problems and asking people to confront the negative aspects of living with dementia. Although people know Alzheimer's or similar type diseases are a major health issue, there is a lot of uncertainty about what the symptoms will actually mean to them. Being healthy incorporates feelings of anticipation, hope, plans for the future, and freedom from fears (Allen & Jensen, 1990). Rather than asking questions based on what Kitwood & Bredin (1992), referred to as "malignant social psychology" (p. 4), I realized I should be asking the participants about the effects of dementia on their daily life. In consequence, my understanding and/or my way of asking questions was influenced by Scott and once I realised why he objected to talking about dementia, I subsequently changed my questions.

Polly was the first participant to take action after a discussion in which she mentioned that Scott enjoyed outdoor sports. He was a keen golfer and used to play several times a week but had given up because he kept losing track of his score. Scott was embarrassed by this but rather than say anything he stopped playing golf. I suggested Polly should approach his golfing friends and ask for their help. At first she was appalled by the idea because she didn't want to tell anyone about Scott's diagnosis: "*I certainly don't want to talk about it yet*", but once Polly recognized the potential benefits of telling other people about Scott's problem, she understood the suggestion more positively. She then contacted three golfing friends and they agreed to support Scott by keeping his score. As a result of overcoming her fear and/or sense of shame Polly was able to improve Scott's quality of life, as playing golf effectively got him out of the house and into doing something he really enjoyed. It also supported his self-image while incorporating physical exercise and social connections.

In addition to the golf, Scott returned to barbershop singing. He enjoyed singing and had been a member of a barbershop group for many years, but participation lapsed after he got lost driving into town. Although his communication skills were impaired, there was nothing wrong with his singing voice, therefore I suggested that Polly should encourage Scott to rejoin the group. At first Polly had to drive him there and back, but before long another member of the group, recognising Scott's cognitive decline, agreed to pick him up and bring him home. The action which followed this fusion of understanding proved to be invaluable to Scott. It gave him a sense of purpose as well as helping to structure his time. For instance, he would mark time by his "*golf days*" in that he would say "*on golf days*" I do this or "*if it's not a golf day*" I do that. Scott continued to play golf twice a week for over a year until visual perceptual deficits severely impacted his ability to hit the ball. Nonetheless, he maintained his membership of the barbershop group for longer.

Another catalyst for action came when I was seeking participant input to a paper I had written for the Alzheimers New Zealand Conference in Wellington. The paper incorporated preliminary findings from the research and in keeping with my commitment to the action research process which involves participants' in the analysis I consulted three dyads about my interpretation. Bernard and Rita were one of the three who agreed to read the presentation and feedback. In the course of conversation about the conference I came to realise that Bernard was overtly interested and so I suggested they should consider attending.

During data collection the following week Bernard pursued the topic. Conscious of his desire to learn more about dementia I suggested that Alzheimers New Zealand conferences are a valuable opportunity to network and learn from others in a similar situation since some presenters, and delegates, are also living with dementia. Moreover, I advised that Professor Richard Faull was a keynote speaker, knowing from previous conversations that Bernard was impressed by the work of Prof. Faull: "*he's very good, a straight talker, tells it like it is.*" Reiterating my advice to attend, I argued that the conference is also a means of learning about overseas trends from international speakers. In this instance, the speakers came from Canada, the United States, and Australia.

In essence, after taking time to ponder on the idea and consider flights, accommodation etc. Rita and Bernard did attend the conference. Consequently, in reaction to one speaker's message: "*don't try to care for someone with dementia alone*" their thinking changed. Previously Bernard, who has a heart condition, had been adamant that he and Rita could manage on their own. Upon their return, they asked their daughters for support.

That was a tremendous help by the way, thank you. It was an exhausting trip but very worthwhile. Listening to that bloke talking about the impact on his health, trying to cope on his own, I thought right I'm going to make some changes. We came home and I told the girls they will have to help more and they are.

Between them they have worked out a system whereby the girls pick Rita up one or two afternoons a week and take her out so that Bernard has time to himself. He is very pleased about this change and stated he enjoys the space.

It's very good because I never go anywhere or do anything when Rita goes out I just stay at home but I manage to have time to think... We've set up a routine, it gives me time on my own, time to relax... I've got no other people to think about I can just do or think about what I want... Parents don't want to be beholden to their children but...

Rita: This has happened, there's nothing much I can do about it, so let's get on with living the best we can.

Bernard: That's the healthiest attitude I think.

The process of understanding that culminated in this action was grounded in imagination, and coming to understand through dialogue. Bernard's desire to learn was the precondition that opened up an opportunity to find new ways to manage the debilitating symptoms of dementia. According to Kögler (2005), it is important to note that dialogical insights enable us to distanciate ourselves from tacit assumptions and practices and thereby allows for a positive reconstruction and reaffirmation of our ideas and actions. (See Appendix O for further explication of the action research cycle underpinning this account).

In searching for ways to support the participants, on more than one occasion I voiced the opinion that having dementia is not something of which they need be ashamed. Rather than hiding it, they should take the initiative and tell people they have Alzheimer's disease, thus giving people a chance to understand. Following Mick's disclosure about communication deficits, I suggested that he should ask people to speak more slowly and thus he may find

they would be more helpful. The next time we met, Mick related the story of a recent visit to the local hardware shop. After taking time to find what he wanted, and getting hard looks from the sales people, he was at the counter fumbling with his money. Believing the man who was serving him was getting impatient, Mick said to the salesperson: *“I’m sorry I’m a bit clumsy, I’ve got Alzheimer’s.”* Mick said he was pleasantly surprised to find the man’s attitude changed immediately and he said: *“Sorry mate, take your time.”*

In my normal daily interactions, such an event would not necessarily give me pleasure. Nowhere that is, except in the course of using critical hermeneutic theory to underpin this action research project attempting to understand the experience of living with dementia from a participant’s point of view. I was delighted to think that our dialogue had culminated in a conversation that enabled a broadening of understanding. Since he had already reported lack of confidence hampers his capacity to interact with others, I was very pleased to hear that Mick had explained his situation to the sales person. Once a person is aware of the loss of relatively simple and mundane skills such as finding the right money when buying goods or following simple instructions, to the more complex, such as those required for employment and social activities, it is easy to understand reactions of frustration and poor self-image (Sabat, 2001). However, feelings of self-worth and self-esteem are not determined solely by the things people do, rather these feelings come from the personal awareness that others notice, and respect, what one can and cannot do (Wilcock, 2003).

Similarly, reflecting on a conversation in which Mick acknowledged his desire to return to the gym, and aware of the increasing evidence which indicates that exercise enhances cognitive ability, I pursued the question of a green prescription³ for Mick in the hope that he could be encouraged to go to the gym during the week. Marianne indicated in conversation that she would support the initiative. Apparently, he had previously been a gym member but had given it up because of the cost. He said: *“Keeping up exercise is virtually the best thing to do but then because it’s sort of impeding the cash flow it might be*

³ A green prescription is written advice from a health professional (usually a GP) recommending a person become more physically active as part of their health management.

prohibitive.” This prompted a question on gym subsidies from which the following conversation ensued:

Mick: *Well, it was the doctor who said to go to the gym...but then when I went along they said, this green card, that's what they called it a green card.*

Grace: *Is that something that you'd still be interested in doing?*

Mick: *Well yeah, definitely, if it fits*

Grace: *It would give you a purpose in the day*

Mick: *I was thinking...the subsidy, whatever they give you, it would be peanuts but I mean, it could help.*

At the time Marianne was keen to have Mick go to the gym but she had not actually taken the initiative to follow up on the idea. Consequently, I made inquiries to find out more about green prescriptions and their eligibility criterion. Initially there was some doubt over whether or not Mick was entitled to one. As it turned out he was, because of the chronic nature of his health condition. Mick had to go back to his GP to get a green prescription which meant he could go to the gym for two dollars a visit. Unfortunately, my attempt at intervention was not entirely successful because in conversation some months later Mick explained that he felt intimidated by the gym instructors: *“They don't try to help. I mean they see you standing there and they look at you as if you are stupid.”*

There are two points of interest here. Firstly, believing gym staff would not intentionally ignore Mick, rather than a deliberate lack of attention, it is assumed that the staff simply did not understand the difficulty he was experiencing. Gadamer (1976) would say the universality of language was missing inasmuch as, unlike his previous experience with the salesperson, Mick did not enter into dialogue with the gym instructors to seek their help, which would enable them to understand his problem. Secondly, given that Mick said his GP originally suggested he should get more exercise, the question arises as to why the GP did not give Mick a green prescription. Here again, less enlightened understandings have not benefitted from improved knowledge. Knowing that people with dementia often lack confidence, or may have decreased motivation to act, the GP could/should have put the process into action.

Finally, following a focus group meeting, Dutch and Moses indicated they wanted to learn more about the cognitive enhancing drug, *Aricept*. Discussion relating to this drug during the meeting had caused Moses to think and act on his reflections. Apparently when Dutch

was diagnosed with Alzheimer's disease five years previously, no medication was recommended. Now, having listened to the other participants, Moses wondered what, if anything, they had missed. He wanted to know if they should try *Aricept* to see if it made a difference. Rather than influence their decision one way or the other, I offered to send literature based on scientific evidence outlining the pros and cons of cognitive enhancing drugs. In that way, they could make an informed decision for themselves. After reading the literature, Moses rang to say they had decided not to use the drug since it would seem that there was no sound proof of its effectiveness. To further explicate the action cycle involving direct interaction with the participant dyads, a summary is presented in Table 5.

Table 5: Summary of action at participant level

Person	Reflection	Action	Evaluation
Researcher	Realized participants sensitivity to the use of language when gathering data, for instance, the word dementia	Reflexively changed my language, choosing words more carefully.	This action increased my awareness of how language influences understandings. Recognised that participants tend to internalize the stigma.
Polly	Concerned over Scott's obvious isolation and lack of daily activities.	Enlisted support from friends.	Action increased opportunities for Scott to engage in familiar daily activity.
Bernard	Desire to learn more about dementia.	Attended Alzheimers NZ Conference (2007) and as a result changed attitude towards caring for Rita independently.	Actions resulted in new understanding of the importance of support.
Mick	Conscious of feeling undermined by other people's attitude	Challenged what was perceived to be a negative attitude while shopping.	Action enabled maintenance of dignity and self respect in light of a negating attitude.
Researcher	Concerned over apparent lack of occupational options in the community	Explored activity options in the community to encourage a balanced lifestyle.	Action raised community awareness of the needs of people with dementia.
Moses	Wondering about the benefits of medications	Sought advice regarding the use of acetylcholinesterase inhibitors to offset decline. Current literature recommended and read.	Action enabled an informed decision not to seek prescribed medication.

Summary

Changes in cognitive ability announce the disease in various, often negative, ways. Yet many of the stories related in this chapter show the possibility of living positively with dementia. My approach to understanding the ways of being in the world with dementia is based on the assumption that human lives are situated within meaningful occupations, activities, relationships, and commitments that offer both possibilities and constraints for living. People are situated within the world through complex understandings of the world. These understandings influence ways of being and acting in the world at any given point in time, in a familiar way of life, in a particular social context. Being situated means that one is neither totally determined, nor constrained, nor radically free in how one acts. Rather one has situated possibilities, certain ways of being that present themselves in certain situations. Equally, there are ways of being that are not available to the person. Since the everyday world presents an ongoing challenge to participation in daily activities, knowledge of the ways in which participants function in their world has relevance. Living with dementia pervades every aspect of life, it is always there, in all ways of being-in-the-world. To deepen this understanding, the following chapter will address the ways in which being different influences the experience of living with dementia.

Chapter Six

Difference: A Socially Constructed Context

“The object of intellectual thought is to think differently”

(Foucault, 1926-1984)

Difference transforms understanding by challenging preconceived ideas that are identifiable only when we become aware of a different way of thinking. This insight moves us towards the realisation that recognising difference in the experiences of people living with dementia is an opportunity to learn, to expand our knowledge, and to emancipate. Understanding difference may be the basis for innovation, change, and progress.

A simplified definition provided by Currie (2004) describes difference as the opposite of sameness. By relating the word *difference* to its opposite, Currie goes some way to explaining its meaning but that meaning is dependent on an understanding of the relationship between the two words. The oppositional relationship has significance for people with dementia who appear different because they deviate from the norm; they are no longer perceived to be the same. The concept of difference with all its diverse meanings is the focus of this chapter. The relational view addressed here includes: the social aspects of difference with regard to personal and public attitudes; the difference between young and older onset dementia, both in terms of how the participants themselves respond to the onset of dementia and services available to support them; and gender differences in approaches to care.

In order to grasp the importance of the critical meaning of the word *difference* from a philosophical perspective, it is necessary to reconsider the tenacity of certain problems in society. The roots of this tenacity are grounded in language that is a taken-for-granted means of relating to the world. In other words, language is incorrectly thought to be an impassive guide to entities that exist in the world, or a list of differences discernible between things. For instance, gender differences between men and women are completely taken for granted because they are deeply fixed in our language system. So, whereas language demonstrates our essential social abilities, this varies between people and is not in itself definitive of the basic differences between people (Calhoun, 1995).

Philosophical insights

I use the work of Jürgen Habermas to explore the theoretical and practical implications of the politics of difference because more than any other critical theorist, Habermas has been used in analyses of the health-care arena (Cheek, Shoebridge, Willis, & Zadoroznyi, 1996; Fardella, 2008; Godin, Davies, Heyman, Reynolds, Simpson, et al., 2007; Lawrence, & Doolin, 1997; Winter & Munn-Giddings, 2001). Habermas's version of critical theory is a means of bringing together interpretive ways of knowing with causal explanations. According to Habermas (1973), a higher level of knowledge can be achieved, emancipatory knowledge, when technical and practical interests are combined. Further, he argued that the issue is deeper than simply biasing theory or practice towards one group or another; at the core of the matter is difference.

Habermas displayed a rare understanding of human nature and social practices, one that assumes all significant differences can be resolved, at least in principle, on the basis of a rational discourse. For Habermas, the importance of discourse lies in the fact that it provides a justifiable way of challenging beliefs (Edgar, 2006; Kemmis & Grootenboer, 2008). Since Habermas has theorized on a great variety of issues, and with each new publication his theories continue to be developed and reformed, no claim is made to adhere to one theory. In the pages which follow, I draw from his theories of communicative action, cognitive interests, administrative power, and general social theory to expose important insights, and to analyze various aspects of difference in their socially-constructed context.

Personal structure of difference

My first real insight into the complexity of attitudinal differences that shape the world of people with dementia came in conversation with Mick. Initially, Mick was diagnosed with Alzheimer's disease in 2003, when he was aged 56. That diagnosis was later changed to one of Lewy Bodies Disease. Mick readily acknowledged that he likes a simple life: *"If it's easy I'll go that way."* This was underscored by his reply to a question about coping with challenge: *"I keep the newspaper up."* When Mick admitted that some days he does not get up *"Until nearly lunch time"*, I asked why he stays in bed all morning. Mick stated: *"Because there's no reason to get up."* Reflecting on the conversation later, I came to see the significance of difference in the attitude of people with dementia.

Different status

Mick was previously involved in the manufacture and maintenance of steel products. He resigned from his job not long after being diagnosed and so perceived himself to be different to others in his social group because he, and not his wife Marianne, who worked full time, “*Should be the bread winner.*” In his opinion, other people look down on him and consider him lazy, “*A bludger ... because I look physically well.*” Habermas (1984) argued that people tend to adopt the principles and viewpoint of their social world and ultimately these perspectives come to shape their personal point of view. At the time of data collection Mick worked one day a week doing unskilled jobs such as sweeping the floors in his brother-in-law’s engineering factory. When asked how he felt about what he does, Mick shrugged his shoulders and said with some irony, “*It’s a job... I’m not allowed to touch the machines*”, thus identifying a difference between him and others in his workplace and also to his previous way of life. There was no time to ask Mick if he resents that proviso before Marianne followed up with: “*They have a good laugh apparently from what I hear.*”

Judging by Marianne’s response, on one hand it would seem that being with people who are prepared to overlook a mistake decreased the likelihood of Mick being exposed to negativity. By attending to and supporting his intact abilities, the people he works with avoid undermining him (Sabat, 2001). On the other hand, the difference between being and its interpretation lies within the language itself (Kögler, 1999). In recalling his work experience, Mick indicated that if he repeatedly makes the same mistake the reaction from others in his workplace is negative: “*It’s the same old story, you do something that’s funny but the next time you do it, it’s not funny anymore.*” Not only was his work role very different to past experience as a result of his dementia, it would seem the attitude of his workmates adversely affects his self-respect.

Maintaining self-esteem is closely aligned to the actions of other people in society. Exposing people with dementia to negativity affects their sense of self-worth (Sabat, 2001). In response to a question about the other things Mick does during the week, the following discussion developed:

Marianne: *His sister's got a little stall down at the market and she makes door stops and so he's going to fill up the bags. I don't think he really likes doing it but you know.*

Grace: *It's something to do.*

Mick: *Yeah;*

Grace: *Do you find it a bit demeaning, Mick?*

Marianne: *I don't know if he finds it demeaning. His sister is a bit of a chatterbox.*

It is important to note that on more than one occasion during these conversations when my question was directed at Mick, it was Marianne who responded. This was a recurring theme with a number of participants during data collection and it is easy to understand how this may erode identity and self-confidence.

Mick had earlier stated that his sister fusses too much and tends to “*Treat me like a child.*” It was obvious he felt belittled by this attention and dislikes being treated differently even though he qualified it by saying: “*She means well.*” To see oneself, and to be seen by others primarily in terms of assumptions around what one can and cannot do, inevitably weakens self-confidence, thus reinforcing feelings of incompetence (Christiansen, 1999; Clare, 2003a; Friedell, 2002; Kitwood, 1997). Depression is manifest in the idea that nothing can be done to improve conditions that are hurtful, painful, and/or detrimental. That is, depression can be a reaction to a loss of self-image, self-respect, and social standing (Sabat, 2001). Although Mick was taking Prozac to help him counteract depression, it did not seem to offset a negative attitude.

Pessimistic attitudes

Whereas those close to a person with dementia may not notice when a loved one is feeling down, there are times when the difference is announced anew. Marianne was very surprised to hear Mick say that he sometimes feels depressed. “*I wasn't aware of it*”, she admitted. Negative thought patterns are based in a negative attitude and when linked to the loss of cherished abilities, it is hard to maintain an optimistic outlook. Mick poignantly expressed this when he stated, “*There's no reason to get up.*”

When people with dementia act differently, it is often assumed to be a symptom of the disease process. Relatively little thought is given to the notion of other influences affecting the person's attitude. In exploring the depersonalization of people with dementia, Kitwood and Bredin (1992), described the different ways in which people with dementia are

undermined. At that time, the effect of the psychosocial environment on health was just beginning to be understood. More recently, Hughes, Louw, and Sabat (2005) explored the idea that people with dementia are deprived of their social selves: “How people with dementia are positioned, how they are considered and referred to, can itself affect how they are as a person, how they behave, and how they interact” (p. 5).

In trying to be kind, others often treat people with dementia differently and as a result benign intentions are interpreted as pity or patronizing (Friedell, 2003b). Early in the data collection process Bernard stated: *“It’s refreshing to meet someone with an attitude opposed to the sense of inevitability that is presented by some staff at the Alzheimer’s Association.”* Bernard does not attend the monthly carer support group meetings facilitated by Alzheimers New Zealand Inc. because he takes exception to what he perceives to be an attitude which signals *“The inevitability of the outcome.”* The following discussion with Rita and Bernard about the relationship between confidence and other people’s attitude reveals another aspect of difference:

Bernard: *I’m convinced with Alzheimer’s, that loss of self confidence is an integral problem of the disease.*

Rita: *Oh I’m sure it is because when you lose your self confidence, you’ve lost yourself.*

Bernard: *Well everyone tries to take it away from you, especially the Alzheimer’s Association.*

Rita: *Oh, shame they are awfully...*

Bernard: *They do tho’, they automatically take away the person’s confidence.*

Rita: *I have to actually agree with that. I have actually seen that, and felt that, and I know they are well intentioned people.*

Bernard: *Yes, they are so kind to you. They say Rita are you alright? Now are you sure about this or that? This is the attitude. They wouldn’t say that if it was you or me Grace.*

Rita: *That is so right.*

Grace: *Good intentions, but they are misdirected perhaps?*

Bernard: *Oh, they have good intentions, they are delightful people really I think.*

Rita: *You know, they are not seeing far enough. They just see the person [with dementia] and they just make a summation or whatever of the person, and that’s it.*

A little later in the same conversation Rita commented:

I think for instance a person like myself, I’m very sensitive, and I pick up things very quickly, and if I feel patronized in any way at all I hate it, I can’t stand it. People with dementia are very aware of this sort of thing, and if you feel you are being undermined or rubbished it is destroying.

Bernard: *I imagine picking up negative attitudes people will go downhill very quickly.*

Rita: *Without a good attitude life would be very, very sad.*

Depression is commonly associated with dementia (McRae, 2007; Ritchie & Lovestone, 2002; Warrington, 1996) and antidepressant medication is often prescribed to offset the symptoms. Similarly, acetylcholinesterase inhibitors such as *Aricept* or *Reminyl* are commonly used to offset cognitive decline in the early stages. While there is no scientific evidence to indicate that pharmaceuticals slow down the underlying disease, they were approved on the basis of studies showing temporary improvement.

Divergent opinions on pharmaceuticals

Mick was prescribed several pharmaceuticals following diagnosis, including a cognitive enhancer to help manage the symptoms of the disease. However, the following conversation reveals his concerns about side effects:

Mick: *I feel nausea, feel like you want to be sick, it never seems to leave me. The doctor says here have this pill it will probably stop you from... and it makes you worse you know.*

Grace: *Is that since you started taking Aricept?*

Mick: *Yeah.*

Marianne: *But he sort of gets it even when he's forgotten to take his Aricept so I'm wondering if it's his blood pressure pills.*

Grace: *That's the trouble with medications, you often get side effects.*

Marianne: *Yeah, well he takes 10 or 11 a day and well you just don't know what's what.*

Reviews on the benefits of cognitive enhancers are mixed. Claims that they can slow down the progression of the disease have been shown to be wildly inaccurate (Harris, 2006; Salmon, 2006; Saul, 2007). Indeed some experts say that the drugs do not provide enough benefits to justify the cost involved (Harris, 2006). Nonetheless to people involved, be that the person with dementia or their family trying to cope with the symptoms of dementia, these drugs offer hope. Bernard explained: *"We want something that will help our loved one, in any way possible. We don't care what it is, anything. We grasp at straws."*

When I first met Rita she was adamant she would not take drugs to offset the symptoms of Alzheimer's disease and initially her GP supported that decision since she advised that research indicated the outcomes are not necessarily positive. The following flow of conversation captures Rita's point of view:

Rita: *I don't want any medication so I don't see why I should have it.*

Bernard: *I'd be quite keen.*

Rita: *No, no, I can't be bothered with medication. I think if you've got something and, em, ...you face the fact that it's there, and I mean you do the natural things, but well okay this is life.*

Bernard: *Whereas my GP will say, why doesn't she take this? They're in the same practice these two GP's, and em, the woman she won't try it. She says, I've tried patients on it and the results... she's not keen for Rita to...*

Rita: *As an individual, I mean, I feel I've got a say, and I really don't want to try.*

Grace: *Well that's the bottom line.*

Rita: *No, I don't. You know, I know that people feel that perhaps they've got the right thing but as I see it, yes, I've definitely got dementia and eh, if I look after myself and I'm happy, or I'm doing okay, well, I think let's see if it deteriorates.*

The final statement suggests that Rita may think of the drugs as a curative measure whereas Bernard argued that they are a preventative measure. Even though he knows functional decline is inevitable, Bernard eventually insisted the GP prescribe the drug to help Rita retain her abilities but still Rita refused to take them:

Bernard: *We just paid 250 bucks... the GP finally decided, because I pushed her into it, she finally decided that Rita could do with Aricept, so she gave her a script and I picked it up and paid 250 bucks and Rita hasn't taken a one yet.*

Rita: *I really don't think I'm that bad.*

Bernard: *The GP had also printed out a list of the possible side effects and gave it to me... I nearly had a stroke when I saw the list of side effects. I've never seen so many possible side effects from a drug, so that sort of dissuaded me. Otherwise, I would be pushing harder, but I haven't been pushing, so the stuff is sitting there on my bedroom table. And ironically having talked the GP into it we are not using it. We are still using the cognitive therapy.*

Eventually, Rita did agree to take the drug for a trial period of three months. After one month Bernard said: *"I notice no difference."* Consequently they continue to use cognitive stimulation therapy in the hope that both will help to offset cognitive decline and thereby enable Rita to function at the highest possible level. Manufacturers of these drugs claim they delay the progression of the disease process and reduce cognitive decline. However it is interesting to note that research undertaken in Britain has found that as a therapeutic medium, cognitive stimulation therapy produces results that are comparable to intervention with pharmaceuticals such as acetylcholinesterase inhibitors (Clare, Wilson, Carter, Roth, & Hodges, 2002; Clare & Woods, 2004; Salmon, 2006). The implications of this are quite profound since the paucity of effective treatment reflects how difficult it is for medical science to understand the disease. This lack of treatment has contributed to the social construction of what is deemed to be an insurmountable problem.

Drawing from Habermas's theory of communicative action

Kemmis' (2010b) recent description of action research draws on Habermas' theory of communicative action to suggest that researchers should open communicative spaces to question and explore 'the way things are'. Habermas (1984) argued that discourse, in which taken-for-granted assumptions or problematic communications are challenged by way of a meaningful conversation between people, will facilitate agreement, mutual understanding and a genuine consensus of opinion about what to do. For Habermas, communicative action involves two or more people developing and/or carrying on a conversation whereby information considered problematic is discussed with a view to achieving a rationally justifiable outcome. At its most basic, the action would be expressed in plain language as in saying something, writing or reporting something. Alternatively, communicative action might be body language that has meaning. In developing his theory of communicative action Habermas took into consideration the fact that there are different ways of communicating. To that end, he identified three functions of communicative action: to convey information, to establish a social relationship with others, and to express personal opinions and feelings.

Viewed from this perspective, if Mick challenged his workmates and/or his sister about what he perceives to be an unhelpful attitude he may be treated differently. Equally, if Bernard expressed his concerns about patronizing attitudes to staff at Alzheimers New Zealand Inc., then his communicative action may ultimately benefit others seeking advice and/or services. Positive and accepting attitudes do much to maintain people's confidence. Similarly, pharmaceuticals are commonly used to minimize the effects of neurological impairment (Perkins, 2004; Sabat, 2001; Snowden, 2001) be that cognitive decline or depression. Reporting the positive and negative aspects of pharmaceuticals would better inform people of their benefits and limitations. Even so, as Bernard pointed out, following a diagnosis of dementia, many people are desperate for something to help offset the predicted decline, because they need to have hope. This has particular relevance for younger people with dementia.

Young and older onset

Whereas everyone's experience of dementia is unique, the differences between young and older onset are distinctive. Personal life experience, family circumstances, and physical

ability all affect the way the symptoms of dementia are manifest. Still, the subjective experience of the symptomatic differences between young and older onset vary, both in terms of the type of dementia involved and in the effect on the person, and his/her family.

Diverse manifestations

One of the first problems younger people face is the question of diagnosis. As with other mental health issues, presenting as ‘sick’ when appearing physically fit can make it difficult to obtain an accurate diagnosis. Often the early symptoms of dementia, such as poor memory, concentration, lethargy, and lack of initiative, also signal depression. Diagnosis becomes even more complex when memory loss is not the initial presenting problem. Rather, atypical symptoms such as behaviour and personality changes, language difficulties, and incidents of psychiatric pathology may be prevalent. For instance, delusions and/or hallucinations are more common in young onset dementia (Reed, Cantley, Clarke, & Stanley, 2002). Whereas it may be possible to understand the reality of dementia in older age, it is more difficult to accept at an earlier age (Tindal & Manthorpe, 1997). Greg was 62, when he began to make mistakes at work. He would get confused and his wife Fiona, noticed that his comprehension seemed to be impaired. A summary of the ensuing course of events follows:

Fiona: Initially treated for depression, but when his symptoms continued he was referred to a geriatrician. After several tests and a clear MRI, he was given a diagnosis of possible early Alzheimer’s disease however Greg refused to believe anything was wrong. As time progressed so did his symptoms, poor judgment, sleep disturbances, restless legs, hallucinations, loss of fine motor skills, and withdrawal from activities. He developed a tremor in his hands, voice tremor, quiet speech, and loss of initiative. Everything became too hard and there were distinct changes in his gait, posture, and facial muscles. Greg continued to be monitored by his geriatrician at three to six month intervals. By now he had been diagnosed with a benign essential tremor. Greg read up on essential tremor and decided that was what he had, not Alzheimer’s. The hallucinations became more frequent, a faceless woman in a long dress, a younger woman with a lot of curly hair, and one night three leering guys guarding the bathroom door. Following surgery to his left knee the pain medication affected him badly. He conducted an unseen orchestra, he believed the walls were running with water, and he talked himself hoarse. In the weeks that followed his tremor increased and his voice became croaky and hesitant. Loss of appetite meant loss of weight, at one stage he said he thought he was dying, he became abnormally sleepy. He was checked for stroke, heart attack, and aneurysm. He was referred to an Ear, Nose, and Throat specialist who confirmed the evidence of tremor in Greg’s voice box, and tongue, nothing else showed up. Lewy Body [sic] disease was first mentioned by the senior social worker at Alzheimer’s, Greg’s medical team subsequently discounted Lewy Body [sic] disease. [Eventually] he was referred to a neuro psychiatrist and at the end of the first visit the psychiatrist gave Greg a

diagnosis of Lewy Body [sic] disease. [Six months later Greg was still] under psychiatric care with slight but limited success. In February we joined the Parkinson's Society and Greg improved markedly. Medications began to take effect and life returned to a degree of normalcy. Now diagnosed with Lewy Body [sic] disease, in an abrupt departure Greg started telling everyone about his disease. As the year progressed and he started to feel better, he again started to doubt the diagnosis, he was positive he had Parkinson's and only Parkinson's. He did not have dementia. Under pressure, our general practitioner referred Greg to a neurologist who diagnosed a 'text book' case of Lewy Body [sic] disease. The neurologist agreed with the psychiatrist that Greg's onset had been subtle and present for many years.

The time span before reaching the final diagnosis was more than six years and, while not indicative of all the younger participants in this study, it clearly shows why younger people experiencing symptoms of neurological impairment live in an emotional turmoil. Those who participated in this study reported experiencing emotions of “*disbelief, shock, anger, loss, insecurity, hopelessness, and shame.*” Although older participants also experienced some or all of these emotions, they seemed more able to reconcile themselves to the diagnosis. Based on the knowledge that only one of the older participants was prescribed antidepressant medication following diagnosis while all of the younger participants were started on antidepressants, there is an assumption that the younger participants experienced a more profound depression. The discrepancy between living with the symptoms of what is commonly thought to be an old person's disease and a younger person's beliefs about themself as a person of a certain age, with a higher level of physical ability, is significant.

Declining abilities

Another key difference is the fact that younger people are often more physically able than older people and the loss of outlets for their energy creates a frustration which increases the challenges they experience. Additionally, all the participants in this study with young onset dementia still had positions of responsibility in their workplace at the time of diagnosis. Following diagnosis, only two of those participants continued working for a time in a less responsible position. Cognitive decline has major consequences in a work environment and when work has been a source of satisfaction and pleasure, the loss of self-image, ability, status, and identity can be devastating (Luscombe, Brodaty, & Freeth, 1998). Several of the participants with young onset referred to this in discussion.

Greg: Used to be I'd do as much as I could each day. Before I had this trouble, I mean, when I was working fully, things never seemed to faze me. If anything, I liked a challenge but that ability I had is seemingly gone... I always enjoyed a challenge...

don't go running to somebody else, work it out yourself... Now the days are long... because I can't do the things I would normally do.

Ron: [I was] *one of the first computer users probably in this country... now I can't use the phone... I get grumpy... another thing I can't do... another loss.*

Gran: *When I did my housework I did it properly, and I've brought the kids up to be tidy. You do it once, you do it right. And that's what I taught. See I used to manage the cafeteria... and then the cookhouse and I always used to make sure everything had to be clean because I wouldn't stand for less. You know it's gotta be tidy and that. Now... I've slowed down, I'm not as fussy as I used to be.*

Pop: *Well the house has changed, it's not as clean as it was... Before this came on bloody hell all that stuff on the table...*

Gran: *No, never would have allowed that. It's not dirty, it's untidy but it's not dirty. I couldn't stand that. You see some days I feel like doing things so I do it. Other days I don't feel like doing it so I don't do it.*

The focus on 'doing things' is clearly evident in all the participants' dialogue because daily activities are an essential aspect of life. Polly had tried to engage Scott in group activities being run by a branch of Alzheimers New Zealand Inc. but after two visits Scott, who was then aged 60, refused to go back. The following discussion describes their experience:

Polly: *We went to one of their Wednesday groups and Scott thought they were boring. It just wasn't him mainly.*

Grace: *What do they do at the groups?*

Polly: *Well we had a cup of tea and we were introduced to the other ones. Some had caregivers, some didn't. Most of the caregivers left. That was their time out for them about two hours. So after that they put them on a bus about six of them and they went to places, they went to a car museum or something like that. I don't know what they did the other time but he just didn't like it, it just wasn't him. The age group was older and it didn't work out, he just didn't like it. So then they eventually got a guy who was from the North Shore who came along who they employed as a fieldworker and he is very pleasant ... but nothing really came of it. I mean nothing positive. There were no suggestions or anything... he spent a couple of hours and it was just a nice chat. He came once and then I, in the end, rang Alzheimer's Association after I talked to you to see if there was something else, if maybe they could suggest something like in South Auckland. ...The result of that was nothing really, the fieldworker came to visit him again but that was that, so we've had no contact with them and they don't really seem to know... it was just too hard, I think it was in the too hard basket. I said to her "Well why don't you go, maybe you could go to Manukau to see how they've done it and maybe you could get some ideas from them" and all she did was acknowledge that there is a major problem for younger men.*

At a later meeting, I asked Scott why he did not want to attend the group. He was quite definite in his opinion that: *"Och, it wasn't for me, they just weren't my type... I wasn't comfortable with them."* Perhaps Scott perceived himself to be different because the others

were all older than him. He alluded to this when he said: *“Physically I am fine, I’m not ready for that”* implying that he had more physical ability than others in the group.

As mentioned previously Scott spent a lot of time on his own because when he retired, Polly returned to work to supplement their income. Knowing Scott had previously worked long hours, I asked again what he does during the day while at home alone:

I take it quite slowly... unless it’s a golf day... then it’s out the door and away. When I get back later in the day probably about 12 – 12.30 or so, then I have lunch. An’ then I lie down an’ look at the paper an’ do all that stuff. It’s a bit of a routine.

In fact, there was no doing *“all that stuff.”* Polly reported that when he was not playing golf Scott did very little during the day. To enable him to feel useful, Polly encouraged Scott to help with household tasks by leaving notes in the diary on the kitchen bench. The tasks involved things like hanging out and/or bringing in the washing, and raking up leaves but as she said *“there’s only so many leaves in the garden.”* Since Scott is an ardent sports fan, Polly had Sky TV installed hoping it would keep him occupied. She said: *“I do feel guilty because he’s on his own all day. It’s hard, he just sits and watches television if he remembers how to turn it on. He watches sport but essentially he’s just sitting there.”* Unfortunately Scott was unable to use Sky for long as a result of his diminished processing capacity. Even though Polly left very simple instructions taped to the coffee table he was eventually unable to tune into the sports channels.

Similarly, listening to music had been another favourite pastime but this was not an option because new technology meant Scott could not turn on the CD-player. Being alone, he could not overcome these challenges. Whereas a reduction in daily activities is commonly accepted in older age, the subjective experience of younger people is very different (Bryden, 2005; De Baggio, 2002; Friedell, 2000; Taylor, 2007). When memory deficits are coupled with a deteriorating ability to do things and to use objects in general, younger people become more withdrawn and isolated from their social world. They are in a fundamentally different existential predicament to that which usually defines family life and/or the social lives of other people of their age. In contrast, older participants seem more relaxed and accepting of declining abilities.

Older people have reached a time in life when some decline is not only socially acceptable, it is expected. When diagnosed with Alzheimer's disease at age 81, Harry was not unduly perturbed according to his wife Betty. He knew his health had deteriorated but he accepted that. Betty cares for him with the help of a caregiver who comes in three times a week to assist with showering. Before retiring, Harry held an executive position in his workplace and as a result led an extremely busy lifestyle. He was a very social person with lots of friends. Both he and Betty had traveled extensively, but Harry was now content to live life quietly:

I sort of know that I am having a problem at times... I realize that I'm in a stage of my life where I need a bit of help... slowed down a bit yes, but there must be a lot of people have the same problem. I just love sitting here looking out... it's nice to know that I can look out the window and think hey! I'm still here.... I'm quite happy and I am very lucky with my wife and all my friends... When there's nothing else to do, I come and sit in this seat and look out the window. I recognize where I am and what I'm doing. Oh yes, I've had quite a career going back. My memories, well I've got the war and I survived that, yes I survived alive. Yes, it goes through my tired brain.

Harry spends a good portion of the day sitting looking out of the window. If Betty has to go out she takes him with her. She said that he is happy to sit in the car and watch the passing parade of people while waiting for her to complete the tasks she set out to do. The fact that Harry does very little for himself did not bother him at all, in fact he seems unaware of it. Harry said: *"I shouldn't be bored ... it's nice to be an old bugger sitting here listening and talking. It's nice to be able to do that."* Perhaps his sense of satisfaction can be attributed to the fact that he has lived a long and full life. Unlike the younger participants, he is content with the things he has accomplished. Harry's attitude to his way of life reinforces the difference between younger people and older people with dementia. Younger people are not yet at a stage in life when they are ready to sit back and reminisce and many still have family responsibilities.

Changing family dynamics

The symptoms of dementia impact on family dynamics especially if young onset dementia occurs at a time in life when people hold multiple roles. Inherent in these roles are responsibilities as parent, partner, householder, homemaker, adult child of ageing parents, and being a sibling. A diagnosis of dementia has a ripple effect on these relationships and causes them to change both inside and outside the family. Most of the participants with older onset said they felt supported by younger family members inasmuch as they see them

regularly. Alternatively, many of those with young onset did not. For instance, Greg and Fiona seldom see their daughter who lives down country, or their son who lives nearby. This, despite the fact they had previously been a close family unit. Equally, they feel cut off from other members of the family circle:

Fiona: Those with family ties, they're a lot better off because family take them out. They go to the movies whereas we don't have that and we do find the lack of family support quite stark. There's one son here, ...he doesn't visit, we can't rely on him for anything. Greg has got one sister here...she's not very sympathetic...or empathetic either. My sister is in the Bay of Islands and my brother's quite happy not to help.

Other participants had similar experiences. Scott and Polly's son lives in a nearby suburb but he seldom visits:

Grace: Does C come over at all?

Polly: I don't know if it's that he's embarrassed or I mean he's got 2 little kids and he's one of these people whose got his job ... he does his best so I don't say much. I mean I told him about the diagnosis and then I think you know as far as C is concerned you know he can't do anything about it.

Grace: But it would be helpful for you.

Polly: Yeah, yeah, I mean they don't come a heck of a lot, about once a month or so.

Changes in family life are a normal occurrence but the changes that come about within roles and relationships when young onset dementia occurs are significant. Whereas the person may grieve over their inability to fulfill a parenting role, each member of the family is experiencing grief and loss over the diagnosis in their own way and in their own time. There is also a higher probability of younger family members being concerned about genetic origins. There is little data on this issue, but it would seem that it has more impact on families living with young onset, than for older people with dementia. Children are afraid the condition will prove to be hereditary, or as Polly said “*contagious*.” She raised this topic at a focus group meeting:

Polly: I'd like to say from a personal point of view, earlier onset it actually affects...our children. My mother had Alzheimer's at a later age and that didn't seem to worry us but my children, because Scott got it young, now do worry about it for themselves. It's a big burden for them.

Pop: That's right...What's in store for the kids? Mum or dad struggle along but then all of a sudden there's the kids to think about.

With young onset dementia, family conflict and loss of cohesiveness can stem from embarrassment, fear, the loss of a role model, sadness and an overwhelming sense of responsibility. According to Habermas (1971) an oppressive reality absorbs those within it.

This ultimately impacts on the whole family's reality (Friedell, 2000; Kitwood, 1997; Sabat, 2001).

Drawing from Habermas's concept of cognitive interests

When the ability to be productive deteriorates, and/or when experiences are no longer enjoyable because the challenge is too great, reality as it was known is changed forever. For Habermas (1971) there are distinct realities which exist independently of our actual knowing. Furthermore, it is only when reality becomes the subject of inquiry that the differences between people's reality is revealed. Habermas argued that reality is not determined by beliefs but by a collective process of personal experiences which differ between people. For others to develop the concept of reality in a pragmatic direction it is necessary to grasp this difference. According to Habermas (1971) to achieve mutual understanding in the ways of life, and thus "emancipation from seemingly 'natural' constraint" it is necessary to "establish the specific viewpoints from which we can apprehend reality as such, in any way whatsoever." (p. 311)

The concept of knowledge-constitutive interests is grounded in the reality of human conditions. In this study, the manifestation of symptoms, levels of physical ability, and changes in family dynamics draw attention to the significance of difference between young and older onset dementia. Addressing the physical and social needs of younger people would benefit family members who share a common interest in simplifying a complex situation. Equally, it may go some way towards maintaining quality of life. Linking this knowledge to forms of action intended to emancipate younger people with dementia may help to free them from the social and political constraints that shape their reality.

The reality

To open the way for a more holistic understanding of reality, it is necessary to be aware of the influences that shape people's viewpoint and through that their actions (Habermas, 1971). Habermas (1984) argued that "Understanding meaning is the privileged mode of experience for members of a lifeworld" (p. 121). In other words, understanding is an advantage that may be limited and/or enabled by personal experiences, knowledge and beliefs about our ways of being in the world, and our moral standards. Harry and Betty identify their roles within their relationship in keeping with the values of their era. Harry was the breadwinner and Betty was the homemaker. Similarly, Ron and Ann had shared

responsibilities until Ron became unable to engage on an equal basis, then a blend of decreasing ability, increasing dependence, and personality changes impacted on their world.

A changing world

The following account of Ron's and Ann's reality of daily living with declining abilities and increasing dependence due to young onset dementia reveals their different world. Ron was the youngest of the five participants with young onset dementia; he was diagnosed with Alzheimer's disease when aged 54.

Ann: *When we were both working, he would get the dinner on, you know. I think when you first left work you would actively look around the house and... put a load of washing on, or do this or that to fill in his time and that's it you know, filling the time.*

Grace: *So, do you encounter problems when you try to do those things now Ron?*

Ron: *Yes, but I'm used to it now... I suppose.*

Grace: *Are some things easier to do than others?*

Ron: [embarrassed laugh] *They're all difficult.*

Ann: *I think you hit the nail on the head... some days are fine, other days are...*

Grace: *Can you think of any reason why some days might be better than others?*

Ron: *No, it's just that I get tired.*

Grace: *Some days it's just too hard?*

Ron: *I think that could be apt... I mean if I've done something or [looking at Ann] if I don't do things properly...*

Grace: *Does it make you feel worse if Ann reminds you to do something, or you maybe haven't done it right?*

Ron: *Yeah, yes.*

Grace: *Makes you feel bad?*

Ron: *Yes.*

Grace: *I'm sure she doesn't mean it.*

Ann: *I know, sometimes, as you say it's two people in this situation. If I do get a bit impatient, which I do, you know I'm the first to admit I'm no Florence Nightingale or Mary Poppins or whatever. I know if I do get a bit impatient Ron really takes it to heart.*

This exchange reveals the frustration that may occur when people can no longer engage in activities they want to do. Ron wanted to be helpful, he wanted to “do things” around the house. The impact of this loss of ability is evident in the range of emotions communicated by Ron; embarrassed, inadequate, sad, and even despair while Ann's response revealed her distress and anger at her own impatience. Towards the end of this discussion, when I asked Ron and Ann if there was anything else they could think of that had not been covered in our conversation. Ann raised the issue of occupational deprivation:

Ann: *When I see the guys down at Alzheimer's yesterday and they are all looking for that companionship that they used to have at work. They're looking for something, being able to do something useful. ... The general day-to-day stuff, you know, getting Ron dressed is not a problem. For most people what becomes a problem is when you come home from work, you know Ron has been sitting there all day and so okay now you're the entertainment manager, you know, so let's go out and do something. So it would be great if that group of guys could have something.*

Grace: *You mean be occupied?*

Ann: *Yes, yes they need an occupation.*

Ron: *Yeah.*

There is no doubt that Ron was aware of the problems he was having. Although Ann was resourceful in finding strategies to help Ron overcome various challenges, lack of support for Ron during the day added to Ann's distress. Ann did her utmost to keep Ron at home but she eventually had to accept that she could not care for Ron alone and when coupled with the responsibility of a full-time job Ann reported: *"It is stress that is the final straw."* After a particularly bad weekend during which Ron flooded the garage while trying to help, Ann was advised that he needed full-time care. Ann admitted that among the multitude of emotions she initially felt, there was a vague sense of relief. On the contrary, Ron had dreaded this decision because he wanted to stay in his own home. This situation exemplifies another socially-constructed aspect of the difference between young and older onset dementia. Research shows that many older people with dementia are cared for in their own home (Access Economics, 2008; Banerjee et al., 2003; Melding, 2005) whereas younger people inevitably end up in residential care because services are not available to meet their specific needs.

Ron showed remarkable strength of character and a relatively philosophical attitude toward going into care: *"I may as well face the next hurdle and get over it."* However, finding a suitable facility became a key concern for Ann because the only options available were designed for older people. The consequences proved to be devastating for Ron. According to Ann, following his first placement in a stage two rest home Ron *"just sobbed and sobbed every time I left him, it was dreadful... What I found out later was that some of the residents in the rest home had been taking the mickey out of him."* Because apraxia affected his ability to do things and dysphasia affected his ability to communicate and interact with others, Ron was severely disadvantaged. Within two weeks of Ron entering residential care Ann rang me seeking advice:

I have just had a very traumatic hour with Ron. He desperately needs to be able to do something in the rest home to make himself feel useful. In your experience are there any small jobs that would be suitable for someone like Ron? I can only think of things like picking up leaves in the gardens and of course the weather is not helping. I think if he felt he was contributing, no matter how small, he would be much happier.

The request for guidance came too late as Ron was transferred to Mental Health Services for Older People at the local hospital. Ron did not 'fit' in the rest home because he was a relatively young and healthy-looking man in a facility providing care for older people. I know from personal experience of working in residential care facilities that people moving into institutional care in New Zealand these days are older and more frail. Ron's needs were vastly different to this norm.

Differing needs

The practice of referring younger people to services for older people occurs because there is a lack of proactive and effective planning to meet the needs of younger people living with dementia in New Zealand. Financial decisions, along with reorganization of service development, have not benefited them. Recalling the course of events that led to Ron being moved Ann explained:

He refused to go into the lounge, he refused to sit down and eat dinner... so they moved him into the secure unit. He actually seemed happier there. He could go in and out... and walk around but then I got a call to say they were moving him to Ward 22... because... he was stripping his clothes off and walking around naked.

Grace: What is ward 22?

Ann: *That's mental health services for older people. So they took him there and he was pacing all the time... they were struggling to get him to eat but they did eventually settle him... then I got called into a meeting and they said they wanted to move him to [a specialist dementia unit] I just burst into tears. They took him there on the Monday and he's been there ever since... he's gone down dreadfully. It's only been the last few weeks that he's been eating so he's gone down 22 kilos.*

Grace: What age is he now?

Ann: 59

Grace: *I got the impression on a couple of occasions when I was here that you had maybe talked about residential care and Ron didn't like the idea at all.*

Ann: *That's right yeah. It wasn't too bad to start with. I was picking him up Friday night, taking him back Sunday and taking him out during the week. He was okay with that, but it got to the stage where other residents really turned on him because he was different.*

The progression of Ron's disease was very aggressive and the speed of his physical and cognitive decline took everyone by surprise. Why this happens with young onset dementia

and not in older onset is not fully understood, but in Ron's case there were a number of factors that potentially contributed. Ron was moved between three facilities within three months. Moving a person with dementia from a familiar environment is known to be detrimental to their well-being because it exacerbates the problems the person is having (Banerjee et al., 2003). In addition, he had been given a 'cocktail' of medications to 'manage' the symptoms. His physical health deteriorated rapidly and four months after being taken into care, Ann said he had withdrawn from all social aspects of life and could only walk *"Twice around the [very small] garden."*

In comparison, Harry was eventually taken into residential care due to Betty's failing health. The difference between Ann's and Betty's views of living with dementia is stark. Betty believed that: *"Alzheimer's is a kind disease compared to the pain some people have to endure. Some of the cancers that other people have... it's a very gentle disease, there's no pain and it allows a gradual end to life"*, whereas Ann stated: *"I feel such grief, loss, guilt, and anger at what is happening... This is such a cruel disease, watching the person you love deteriorate, and knowing there is little you can do to protect him any longer."*

Drawing from Habermas's concept of administrative power

In order to explore the relationship between the real values, needs, and opinions of people in society and the ratification of laws, Habermas (1996) introduced the concept of administrative power. Of concern were the actions of governmental power structures in the creation of specific social, welfare, and other policies which affect the lives and actions of people in society. Habermas (1996) argued that government agencies tend to advance their own intrinsic agenda, and policies are a means to achieve external ends. In effect, he was suggesting that decisions and innovative changes are primarily intended to be consistent with the existing policies rather than address the real needs in society. Speaking technically, Habermas viewed the government as a system, and "power is the non-symbolic medium through which it is guided and organized" (Edgar, 2006, p. 4). As such, it is in conflict with the life-world of ordinary people, the world through which opinions, values, and identities are formulated and which give meaning to life. Habermas (1989) advised that the public point of view which originates in the life-world can be transformed into a communicative power through community and educational groups, churches, and the mass media. He advocated that these institutions should act as the voice of public opinion and in

this way influence society's policy makers. He asserted that in a just society, policy makers would address the opinions, values, and needs of people who are subject to administrative powers.

Although there has been a burgeoning of research into dementia in recent years, knowledge of the needs of younger people with dementia remains poor and services provided in New Zealand are minimal. The few services that do exist are grounded in the Health of Older People's Strategy (Ministry of Health, 2002a). The vision guiding the strategy states that "older people participate to their fullest ability in decisions about their health and well being and in family/whānau, and community life. They are supported in this by co-ordinated and responsive health and disability support programmes" (Ministry of Health, 2002a, p. 1). There is no similar vision for people with young onset dementia. Yet approaches to caring are known to influence a person's sense of well-being significantly (Kitwood, 1997; de la Cuesta, 2005). Existing services, although based on the expertise of health-care providers, do not address the needs of people like Ron and Ann whose lives are forever changed by a diagnosis of young onset dementia. This brings me to another point of difference that is rarely addressed in any discussions on care work; the question of gendered approaches to caring.

Gendered approaches to care

What can be known about this socially constructed aspect of difference in terms of dementia is heavily influenced by those who participated in this study. Nevertheless the question of gender differences to caring, the gaps and silences, are tentatively explored. This is not a discussion of gender differences per se but rather, a focus on possible difference in men's and women's approaches to caring as a means of teasing out the complex and contradictory nature of attitudes. In this example, the link between the human need for occupation, well-being and gendered roles is discussed.

Practical differences

In contrast to the younger participants' experiences, Dutch and his partner Moses, continued to live a relatively normal lifestyle. Moses facilitated this by having practical expectations of Dutch and treating him as a human being whose sense of self was important, and whose ability to act meaningfully was intact. To this end they established a

weekly routine whereby they participate in various community activities every day except Friday because Moses said: “*Friday is housework morning – always.*” Furthermore:

Moses: *He’s still so capable of doing so many things which I find quite amazing. Because he’s done them all his life you know. It’s like this house. It looks like a museum, and I say to him if you’re going to have all these things on the walls, you’re going to have to do the dusting and the cleaning. He still does it.*

Dutch: *I do.*

Moses: *I mean he might miss the odd corner or something.*

Dutch: *And he will find it, he goes around with glasses.*

Unlike heterosexual couples of a similar age where housework is commonly thought to be women’s work while men are the breadwinners, one of the strengths in Dutch and Moses’ relationship was that they share everything, including the household tasks. However, as Dutch’s abilities declined, Moses took on more responsibility:

I think it’s important to keep to these routines for Dutch but there’s quite a lot about the house that I do now ... because I do supplementary things ... Dutch does all the vegetables generally, this is in general terms and I’ll cook the meat and make dessert.

In order to discover the extent to which people manifest intact mental and behavioural functions Sabat (2008) argued that they must use their abilities. In the time since diagnosis, Dutch experienced a very gradual decline in his ability to do things and as problems arose Moses, who is very resourceful, looked for ways to overcome them. When Dutch began to stumble while navigating the stairs in their home, Moses lined the edge of each step with a white strip to make it clearly visible. This was a simple but effective solution to a visual perception problem. Six years after diagnosis, Dutch was still enjoying life. Yes, abilities had declined and some activities had fallen by the wayside but Moses said so many people doubted Dutch’s diagnosis that late in 2007 he was reassessed. The diagnosis was confirmed.

Reflecting on the data gathered from Dutch and Moses caused me to consider the possibility that the difference I was seeing might be gender-related. Men and women *care* in very different ways and I came to see Moses’ practical approach to caring for Dutch as very constructive. By expecting him to continue doing the things he had always done, Moses was helping Dutch to retain abilities. The literature describes male caregivers as using instrumental or problem-focused approaches to caring whereas women are said to be more emotional (Baker & Robertson, 2008). In other words, many women instinctively

nurture and in doing so they inadvertently contribute to increased dependence. I suspect dependency is detrimental to people with dementia. A comment from Moses at one of the focus groups reinforces this idea: *“There’s one thing that upsets me a bit, gets me uptight sometimes, is other people step in to help Dutch when he doesn’t really need it.”*

Positive difference

In reflection, I came to realise that participants who were being cared for by men were more sanguine. For example, Gran showed great resilience in her determination to maintain her independence. Granted, she had Pop’s support, but another significant difference between Gran and some of the younger men was her confidence, and her attitude:

I’m determined, until I can’t do what I want to do, I’ll still be doing it. Dementia is not going to control my life... gotta be positive. When I go to bed, I say please God let me have one more day, you know like that. And when I waken up in the morning I think oh well, I’m fine. I’m still here, I’m still able to do things.

Gran’s positive attitude is reinforced because Pop respects their different roles. While Gran maintained her responsibilities in the domestic domain, Pop supported Gran. He did not try to take over instead he said: *“It’s too easy to roll over. Once you’re on a downward slope, you don’t climb back up.”* In Pop’s view:

She is the matriarch of our whānau and that’s extra special. The old patriarch he just plods along on the truck, and she is my trailer. Once we’re latched on together that’s it... Trucking and trailer-ing, for the family, for the little ones.

Rita and Bernard provided another example of how approaches to caring may be influenced by gender differences since Bernard’s approach is defined by his masculinity. Although Bernard had taken over many of the daily household tasks, in the process of caring for Rita he constantly challenged her to think and to do things for herself. This may be a contributing factor to Rita’s positive attitude:

If I’ve got dementia, I’ve got dementia. I’m not going to advertise it to anybody, but if they should know that I’ve got dementia it doesn’t bother me in the slightest. This is my lot, I’ve got my partner and I know that he understands and so this is life. I mean if you’re going to worry about things like that then you are only hurting your own life. This is life so let’s just live it. At least that’s how I see it... I think the personal attitude of the person is important, you can’t get away from that. You know if you accept it and that’s fine but it doesn’t really have to walk with you every minute.

Bernard claimed he is vigilant about not doing too much: *“The caregiver is concerned on behalf of the person with the disease and therefore substitutes for them. I’ve seen myself do*

it... I have to keep telling myself Rita can do this.” On more than one occasion Bernard was heard to say: *“use it or lose it.”* Consequently, he challenged Rita on a daily basis to encourage her to maintain her cognitive abilities. First thing in the morning: *“What’s the day, the date, the month, the year?”* Although this annoys Rita, he persevered because he wanted Rita *“to get those neurons working.”*

Recent studies on maintaining cognitive ability, which include not only memory but also reasoning, attention, concentration, and speed of processing, identify the importance of three things; physical exercise, mental challenges and social activities (Dabbs, 1999; Mountain, 2005; Shenk, 2001). Science has found that when brain cells are not adequately stimulated, they self-destruct. This process is known to be an important factor in Stroke, Alzheimer’s and Motor Neurone diseases, leading to the loss of essential neurons from the adult brain (Coulson, 2008). Since no two human brains are exactly alike, no one challenge will adequately satisfy all people for the same length of time. The range of stimulating activities available to human beings is infinite. For some, physical activity is gratifying; for others, finding and processing information is rewarding; for still more others, working with creative ideas is enjoyable. Regardless of the form of the activity, it is the challenge to the brain cells that is important (Jakobson Ramin, 2007).

Over time and across societies, gender has influenced the division of labour and society has learned to associate caring work with the female gender (Armstrong & Armstrong, 2002; Baker & Robertson, 2008; MacRae, 1995). Interestingly, the concept of difference is closely aligned to the history of feminism. Given women’s empathy for care, feminist beliefs are a useful means of relating understandings (Love, 1995). If we accept that women have been socialized into nurturing and are therefore deemed to be kind, gentle, and compassionate then equally we must accept that men are socialized into being masculine which infers they are strong, independent, and in control (Baker & Robertson, 2008; Eisenstein & Jardine, 1988). These characteristics shape the way in which women and men care for others. In other words, the care provided by women differs fundamentally from the care provided by men. Most of the women in this study have tended to ‘do’ for others whereas the men had a more insular history. By itself this does not define the quality of care, but it could be argued that men’s approach to caring is better for people with dementia because as Kitwood (1997) pointed out, the way in which care is delivered can have a

positive or negative effect on the person being cared for. Doing for others may be a central experience in the life of many women (Oakley, 1992) but in the case of people with dementia the tendency to do too much can be detrimental as it exposes the person to excess disability (Friedell, 2000).

Having reflected on this aspect of the data in great depth I broached the topic at one of the focus group meetings:

Grace: I wonder if as carers you need to step back a little bit and give the person time to do things for themselves... even making decisions, let them make their own decisions. My observations are that often the caregiver takes over.

Moses: Yes, well, I try and get Dutch to... answer questions or say what he wants first and then if he forgets something, or is not quite sure what he's doing, he'll look at me and so I know I've got to sort of carry on.

Grace: Pick it up from there.

Marianne: Yes, I know that I'm at fault for doing that too, sometimes not letting him finish.

Grace: What did you say Mick?

Mick: Yes, yes, yes, [laughter]

Marianne: I think, oh I shouldn't have said that, or I shouldn't have done that, but I can't take it back.

Mac: I should imagine it's the same with most carers trying to help, dash in and do something.

Bernard: I think you've touched a nerve as far as I'm concerned. Can't speak for the others but I do think we tend to substitute, put ourselves in when we don't need to and I think sometimes it's convenience. In my case anyway, I can do that more quickly and when I know what's going to be done. But, I think it can be demeaning, I'm sure it is demeaning to anybody... having the disease, so I have to look at myself all the time. I think that is a valid point that you've made there Grace.

Although my suggestion that carers do too much was predominantly agreed to by men, it would seem that the women at the table also took the idea seriously because they were nodding their heads. This brief insight into gender differences in caring has important implications for understanding approaches to caring for people with dementia in general. While they are not definitive, gender differences draw on, and interact with, other important concepts such as attitudes, and values. While this has not been a systematic investigation, the difference between men's and women's attitudes towards caring has significance for participation in daily activities as well as social aspects of daily living.

Drawing from Habermas's critical social theory

Habermas (1971) used critical theory to analyse society. In so doing, he was seeking a way to offer an evaluation of events in society and to guide political practice. According to Habermas (1984) society is partially characterized by the diversity of the people who abide within therefore to become more responsive to people's needs, justice demands that processes or systems which allow for difference must be integrated into society. This can be achieved by considering the attitudes and beliefs that prevail in society, and wherever possible enhancing them with improved knowledge and values. Habermas recognized the need to overcome difference in the interests of justice (Baynes, 1995). That is to say, justice requires the application of different standards to different people or a greater sensitivity to the diversity and complexity of life. When we come to understand difference, then sensitivity and the necessary disregard for the complexity of life can develop (Habermas, 1971).

According to Minow (1993) the "dilemma of difference" (p. 218) poses a distinct challenge because it is intricately woven into the basic principles of equal rights. Treating people equally requires a judgment about the context in which they are similar. By the same token, to understand differently means to assume a basic similarity in context. This may be why feminist literature poses the question of what exactly is meant by treating people equally:

By taking another person's difference into account in awarding goods or distributing burdens [in any interaction], you risk reiterating the significance of that difference and, potentially, its stigma and stereotyping consequences. But if you do not take another person's difference into account – in a world that has made that difference matter – you may also recreate and re-establish both the difference and its negative implications (Minow, 1993, p. 232).

Such deliberation indicates that the nature of difference is problematic. In attempting to determine which differences need to be resolved and which should be ignored, the conditions in which terms of reference are set up and used as a basis for making judgments of similarity and difference, may go unchallenged. This may be why Kögler (1999) argued that in the interest of understanding, it is necessary to identify differences in society since:

Only through confrontation with another's meaning (or through conflict situations of various kinds) does the interpreter acquire an opportunity to bring into relief – which means above all to bring to conscious awareness – the hitherto unnoticed prejudgments that are recognized as such only through the experience of difference (p. 27).

For Habermas (1971) difference in human interests influences, and to a large degree shapes, both the development of knowledge and the way social reality is perceived. What is more, social justice requires more than theories and discussion. It is a practical issue that demands commitment and purposive action (Habermas, 1984). In response to the question of difference identified in this chapter, the researcher reflexively undertook action to address the lack of community support available to people with young onset dementia. Seeking invitations to talk about approaches to the care of people with dementia at local and professional levels was deemed to be a constructive way to stimulate social change in understanding. Since these issues cannot be addressed and managed within individual lives, they required action at a societal level.

Action at societal level

Deliberating on these preliminary findings contributed to action that was intended to encourage change in people's circumstances and their individual ways of living. That is, identifying the problems incurred through various aspects of difference, reflecting, planning, discussing, taking action, evaluating and discussing again before offering a critical interpretation which recognizes that truth and meaning involved interactions between the interpreter, the participants, and situating socio-historical structures. The goal was "to act in the world, to practise, and to *do* - and not just engage in discourse about it" (Kemmis, 2010a, p. 11).

A great deal of time was spent at different intervals, reflecting on the lack of services available to younger people with dementia. I had been told on various occasions by various people that dementia had been removed from the Mental Health Act because dementia was not considered a mental health problem. This both confused and concerned me because it meant there was a significant gap in service provision if younger people with dementia were not eligible for Health of Older People services nor covered by Mental Health services. Searching the Ministry of Health website unsuccessfully for clarification of this, I decided to contact the Ministry itself. Therefore, I sent an email in which I explained that I was currently engaged in a research project designed to address the daily activities of people with dementia in the community, and in consequence, I was trying to establish whether or not people with dementia are covered by the Mental Health Act in New Zealand. I received a response the following day but it did not answer the question I had

asked so I sent another email. Eventually, I was given the Ministry's website address and advised that the latest amendments to the Act were available on line.

Having previously read the Act to no avail, I sent off another email indicating the lack of clarity in interpretation of the act. In due course, I received a letter from Dr David Chaplow, Director of Mental Health Services (Appendix P). Dr Chaplow advised that people with dementia do come under the Mental Health Act, inasmuch as the definition is based on symptoms rather than diagnosis. I was very gratified to learn this, since the information could prove beneficial to people with young onset dementia. In light of the knowledge gained from the younger participants I wanted to encourage them to try to maintain a balanced lifestyle, and thus preserve a sense of health and well-being by engaging in a variety of physical, mental, and social activities. However, I had also come to realize that few opportunities were actually available to them.

At a later date, I was in discussion with Ann, a research participant who is also chairperson of a branch of Alzheimers New Zealand Inc. In the course of conversation Ann mentioned that a funding round was coming up with the Ministry. I asked about sources of funding, in particular, funding from Mental Health services. When Ann advised that dementia is not covered by Mental Health services, I was very pleased to be able to correct her statement and to have a letter to prove it. In short, I gave Ann a copy of the letter to support a funding application. Apparently during the meeting with people from the Ministry, Ann asked about funding silos for younger people and how they work. In response, the Ministry's representative outlined the process. When Ann asked about funding from Mental Health services she received the standard reply, 'people with dementia are not covered under the Mental Health Act'. In response, Ann produced her copy of the letter from Dr Chaplow, whereupon the Ministry's representative said *"I can't believe this."* It seems the Ministry staff member was unaware that younger people with dementia are covered by the Mental Health Act.

Prior to this outcome I contacted another participant Pat, who had taken part in the research together with her mother Sheryl. Pat was chairperson of a different branch of Alzheimers New Zealand Inc., and she was also very keen to have a copy of the letter. I have since learned that both applications to Mental Health services for funding were successful. The

amount received was not disclosed but I was advised that in both instances the money would be used to augment service provision for younger people with dementia.

Furthermore, in what Habermas might call an ‘instrumental action’ (Edgar, 2006) intended to encourage change in approaches to care-provision, I submitted abstracts (Appendix Q) to numerous national and international academic conferences beginning in 2006. The conferences were convened by professional bodies such as Alzheimers New Zealand Inc., the World Federation of Occupational Therapists, the Dementia Services Development Centre (University of Stirling), the New Zealand Association of Occupational Therapists, the New Zealand Association of Gerontology. A total of 14 presentations, the content of which addressed the preliminary findings of this research project, have been undertaken.

In 2009, prior to a presentation at the New Zealand Association of Gerontology (NZAG) Conference in Wellington (October), I was contacted by Mike Gourley, producer and presenter of Radio New Zealand’s weekly disability programme One in Five. Mike expressed an interest in interviewing me for the programme based on my abstract titled: *Exploring the concept of occupational justice for people with dementia* (Appendix R). The abstract was published in the conference programme. I agreed to have a conversation with Mike and to that end I met with him at an agreed time during the conference. This was a wonderful opportunity to talk about my research with a view to raising awareness of the needs of people with dementia. The programme aired on national radio on December 20, 2009 (Appendix S). The following year, my presentation at the Alzheimers New Zealand Conference in Wellington was recorded live. It was later broadcast nationally in a segment of Radio New Zealand’s Insight programme on July 4, 2010.

In addition, I presented to peer groups such as the Local Area Network for occupational therapists, Mental Health Services at Green Lane, and the Old Age Psychiatry group. Additionally, in response to a request for input to a class project, knowledge and experience was shared with (year 11) children attending Glendowie Primary School. These presentations were intended to inform others of ways to support people living with dementia both in the community and in residential care. See Table 6 for a summarized explanation of action at societal level.

Table 6: Summary of action at societal level

Person	Reflection	Action	Evaluation
Researcher	Concerned over lack of services for younger people with dementia.	Inquired whether younger people with dementia are covered by the Mental Health Act. Written response from the Director of Mental Health Services confirmed that younger people with dementia are covered by the Act.	A new source of funding identified
Researcher	Wondering how best to use information received.	Information shared with the chair of two local branches of Alzheimers NZ.	New source of funding to augment services for younger people with dementia.
Researcher	Aware of the need to challenge prevailing attitudes and to promote understanding of people with dementia's right to live well.	Multiple conference presentations undertaken.	Response indicates people in society are keen to learn.
Researcher	Speaking out about dementia.	Interviewed on national radio.	Raising awareness of positive aspects of dementia.
Researcher	Want to raise awareness of the need for change in societal understanding of dementia.	Addressed peer groups and others.	Informing others of alternative approaches to the care.

In all, my aim was to challenge prevailing attitudes and to promote understanding of the importance of enabling people with dementia to engage in daily activities to assist them to retain and maintain skills and abilities. I also advocated for change in the way people with dementia are perceived. A key focus in the main body of each presentation is the plight of younger people with dementia. Using knowledge gained from participants in the course of this study, my goal was to inform delegates of the significant differences between young and older onset dementia and to emphasize the need for age-appropriate service provision. One can only hazard a guess at the success of these early attempts. Feedback following the presentations has generally been very positive although in some instances there is little comment. In terms of increasing understanding of the complexity of living with dementia, these conference presentations are intended to make a difference.

Summary

In this chapter, I have used Habermas's theories of communicative action, cognitive interests, administrative power, and critical social theory in order to present an analysis of the range of differences that shape the reality of people living with dementia. A close

examination of difference, such as the social impact of difference, shows that people with dementia are curiously vulnerable to attitudes, be that their own and/or other people's. On the subject of young and older onset, two significant differences are highlighted: that of being diagnosed with dementia while still in the prime of life, and the lack of policies and service provision to support younger people with dementia in New Zealand. In discussing gendered approaches to caring, the account is intended to be pragmatic and simply offers an alternative viewpoint. That is to say, it offers an account of men's attitude towards caring for a partner with dementia. This information could contribute to the development of a new way of approaching dementia care and may ultimately help to empower people with dementia. The actions summarized in this chapter all served to open up a space whereby others could view dementia from a different perspective, one that was intended to benefit people with dementia. To complete the data analysis and augment the knowledge gained thus far, the chapter which follows will address notions of power and prejudices.

Chapter Seven

Prejudice and Power

“Prejudices are the biases of our openness to the world”

Gadamer (1900-2002)

Gadamer's notion of prejudice has been one of the most controversial aspects of his philosophy. For Gadamer (1996), prejudice refers to prejudgment, making a decision before knowing all the relevant facts of a situation or event (p. 270). It is important to note that his interpretation of prejudice did not necessarily imply negativity. According to Gadamer prejudices were true in that they were open to expansion and change through ongoing fusion of horizons and false when they were not open to reconsideration or further development. In addition, Gadamer argued that the past is a very pervasive power in the process of understanding. Through embodiment of prejudices and traditions, the past influences all interpretations of understanding. This is reflected in other people's understanding of what it means to have dementia. Shaped by the past in so many unexamined ways, prejudices pervade the fundamental aspects of living with dementia.

A limited, yet more contemporary, interpretation is proposed by Farley (2000), who contends that a common factor in each type of prejudice is a basic set of attitudes which cause, support, and/or justify discrimination. As a consequence, people who are said to be prejudiced respond to others in a more or less fixed way. Word meanings evolve over time. The word prejudice has previously referred to judging people negatively because of their race, religion, or class. Today it is more commonly used to refer to an unsociable attitude towards someone or something, without fully knowing the person or their circumstances. It is also applied collectively and is commonly referred to as “people's thinking: their attitudes and beliefs which tend to favour one group over another, or which tend to cause unequal treatment.” Moreover, prejudice can be “overt and very obvious or it can be subtle and indirect” (Farley, 2000, p. 9). Subtle prejudice is the practice of stigmatisation, which is the result of assuming that all people who belong to a particular group are alike, for instance, people who live with dementia.

Philosophical insights

French philosopher Michel Foucault's work on power and prejudice is used in this chapter to explore the ways in which prejudice influences the daily life of people who live with dementia and their families/whānau. When considering the complex relationships between people in taken-for-granted aspects of everyday life, the concept of power which gives rise to prejudice as developed by Foucault has significance (Powell & Wahidin, 2006). The intention of the discussion is to bridge the gap between the reality of living with dementia and the meanings that resist assimilation into our social world.

Drawing on the work of Michel Foucault

Michel Foucault argued that power practices are largely hidden, everywhere in society. He focused primarily on showing how ideas and practices come into being, and how they acquire power which maintains and transforms them into prejudices (Culpitt, 2006). The practices successfully represent themselves as natural and disseminate themselves so effectively that they remain anonymous, or unexplained (Foucault, 1990). In the context of oppressive power, Foucault understood that dominant power is not exercised simply by physical force but by socio-psychological discourses that shape society's vision of reality. Thus, he advocated that knowledge of language enhances opportunities for participation in dialogue with others so that historical perspectives underpinning power can be transformed and extended. In relation to prison reform Foucault advocated that knowledge development cannot be regulated by the dominant discourses if it is to be in the interest of those described, rather "prison reform must come from prisoners" (Brown, 2000, p. 2). He had therefore listened to prisoners describe their experience of confinement and the power structures prevalent in prisons.

For Foucault, dominant discourses replicate systems of order with potentially devastating effect (Brown, 2000). Foucault (1990) sought fresh ways to see hidden prejudices and to recognize and challenge abuses of power. According to Foucault (1997), power and prejudices are a starting point from which understanding can evolve. In relation to this study, that means finding the prejudice behind the structures of power and the discourses that prevail in society and act to disadvantage people with dementia. In Foucault's view, guarding against unjustifiable distortions that sanction prejudice means seeing the subjective perspective of the person on one hand, and the objective reality of society on the

injustice. Both are fundamental to understanding and responding to the experience of living with dementia.

Support from Kögler

Critical hermeneutics has an obligation both to understand and reveal the ways in which power imbalances and prejudices constrain and distort interpretations. According to Kögler (1999) grasping the political and social conditions under which prejudices came into being is vital to expose the link between hidden background knowledge that sustains prejudices and the prejudgements that shape social understandings. Kögler (1999) echoed the Gadamerian notion of prejudice when he referred to both positive and negative attitudes.

The reality of prejudice

People with dementia and their family/whānau construct their daily life against a background of prejudice. In conjunction with their own pre-morbid ways, the attitude of other family/whānau members, friends, and society at large has a profound effect on how people with dementia and their family/whānau go about everyday activities. When considering prejudice, or the ways in which other people think and behave, attitudes have significance, as the following example from Scott and Polly will show. It has been mentioned previously that although Scott and Polly are still together, prior to the diagnosis they had been estranged for some time. Where Scott found the diagnosis overwhelming, Polly was utterly devastated. Some of her distress may have been related to their personal situation or equally, Polly's mother had been living with Alzheimer's disease for over 10 years. During those years Polly was her main caregiver, although her mother had been in residential care for some of that time. From the beginning Polly found Scott's diagnosis "too hard" to talk about as the following conversation reveals:

Polly: *It's difficult to face up to it. One of my problems... which you might find interesting is... that I don't share things with people. They might know, they might figure something but...*

Grace: *Have you any thoughts as to why?*

Polly: *I don't know. It's strange I don't particularly feel ashamed I just...*

I didn't mind telling people about Mum, and I coped better, but now... there's something.

Grace: *Makes it too real maybe?*

Polly: *I certainly don't want to talk about it yet, although I think I would have access to more support.*

Grace: *I think you would, because people will support you, given a chance.*

Polly: *I think it's a sort of gossip thing you know.*

Grace: *You don't want everybody knowing your business?*

Polly: *Yeah, see I think especially [friend] would be understanding. She has a son who is autistic, I mean she's in that sort of world, similar sort of thing to me so I think she... I mean, originally it was because I sort of just backed off. Yeah, it is just too hard.*

Grace: *Maybe by doing that [talking] you will slowly become more comfortable. Do you think your reluctance is because it carries a stigma?*

Polly: *Yeah, I mean I'm not going to 'cause I don't want to talk to it.*

The sense of shame associated with dementia has long been documented (Kitwood, & Bredin, 1992; Mace & Rabins, 1981). It is commonly assumed that when people are diagnosed with dementia, virtually nothing can be done to help them beyond meeting basic physical needs (Banerjee, 2005; Sabat, 2001; Shenk, 2001). The prevailing view which posits dementia as “a death that leaves the body behind” (Kitwood, 1997, p. 3) is generally accepted and typifies the negative interpretation of dementia. Despite recent research which offers insights into how people can construct meaningful lives regardless of the challenges the disease presents, it is regularly assumed that if a person has Alzheimer's, or a similar type disease, that person is unable to function (MacRae, 2007). This prejudice has given rise to the social stigma around living with dementia.

Social stigma

The stigma of dementia creates barriers between ‘people with dementia’ and ‘normal people’ perpetuating an attitude that isolates people with dementia from the social world. Thus, people with dementia want to hide their health problem by not telling others and/or denying anything is wrong. It is easier to pretend that all is well than to challenge the stigma of dementia (Bryden, 2005; Taylor, 2007). This could well be interpreted as denial, or unawareness of cognitive decline however, such an interpretation is comparable to viewing people's discourse primarily in terms of the diagnosis. Taking time to come to terms with the diagnosis and/or downplaying the experience of living with dementia could equally be interpreted as the person with dementia trying to maintain dignity and salvage some sense of self (Sabat, 2001).

Following diagnosis, Rita and Bernard agreed not to disclose the information. Bernard said: *“We went to Cornwall Park when we first found out about it. We looked at each other and said, now nobody knows about this just you and me, and that's how it will stay.”* This stance lasted for five or six months until Bernard realised it was unfair not to tell their five

daughters: *"We're a close family and they know nothing of this."* By keeping the knowledge confidential they were depriving the girls of the opportunity to understand the challenges their mother and father were facing and to provide support. Furthermore, Bernard recognized they were inadvertently contributing to the notion of dementia as something to be ashamed of. He reversed his decision and strongly advocated that Rita do the same:

I said to Rita eventually, the children have to know so we called them here. We have three in Auckland, and we brought the three over, and sat them down and told them. So it was out, completely in the open. They knew what was going on and from then on we have just continued day by day. Rita chooses not to speak of it, rather like cancer was 50 years ago. It's got a stigma to it Alzheimer's and it shouldn't have. It is a sickness just as cancer is a sickness and you don't have to be ashamed to have a sickness.

However, once the family had been informed Rita confessed she had no intention of telling anyone else. She steadfastly refused to divulge the news to others. On one hand, she claimed to be unconcerned about what other people thought but on the other hand, she didn't want the diagnosis to become common knowledge. Instead, she argued:

I'm very open with the family and all that sort of thing. I mean that's a fact of life and you can't do anything about it can you? But I wouldn't offer this information, why should I offer it to outsiders?

When asked if she was sensitive about having Alzheimer's disease Rita replied *"Oh I'm sensitive outside the family...I wouldn't be wanting to give this information out. I suppose people would observe if they lived with me for long enough but I don't want to."* When Bernard commented that people tend to feel sorry for someone with Alzheimer's disease Rita responded emphatically:

Oh I wouldn't like that...I mean at this stage I'm not terribly upset about it but it could get worse which I believe it does so, well we'll deal with it when it does. I mean you don't like to think about it and what am I going to be like, you know?

Greg was another participant who had strong feelings about discussing the diagnosis with others. Fiona said: *"He totally rejected the idea that there was anything wrong. He refused to even consider the diagnosis let alone talk about it."* At that time, Greg was reported to have a history of poor judgment, Fiona claimed his comprehension was impaired and he admitted his motivation to do things was reduced, but judging by his response to the diagnosis it would seem that he was very aware of the stigma that prevails in society. He

did start taking a cognitive enhancing drug but nonetheless, Fiona said he was adamant that he did not want to talk to anyone about the diagnosis. During this conversation the following opinions were shared:

Greg: *There's a false perception by the public at large, who think once you've got dementia you're no longer part of society, you know.*

Fiona: *The label. We've had a couple of phone calls from friends we've known for a long time... they actually popped in for the first time in years and they said Greg is really lucid and I said yeah well he's the same Greg.*

Grace: *Shame on you Greg.* [Laughter]

Fiona: *And she said, "[friend] had a really long talk to Greg. Is there anything really wrong with him?"*

Greg: *Yeah, because you're still lucid they think there's nothing wrong with you.*

Fiona: *They hear that word dementia and they think of someone in the very final stages of dementia.*

Greg: *That's what it's about.*

Greg went on to say that even some of his family members reject the diagnosis. His sister prefers to think he is just suffering from “*Old timer's disease*”, clearly identifying her own poor understanding. The ways in which others position people with dementia can cause great anxiety which, in turn, may have an adverse effect on how people with dementia interact.

Stigma and anxiety

Concern over other people's attitudes became obvious during a meeting with Liz. Diagnosed with Alzheimer's disease in 2003 aged 72, I first met Liz and Mac just after Mac's 80th birthday. It was observable from the outset that Liz and Mac have a strong relationship based on mutual friendship. Married for 54 years, they have seven children, and as a wife, mother, and homemaker, Liz had previously led a busy life. She derived a great deal of pleasure from being actively involved in her children's lives and was always there to help out with school activities and after school sports. Mac said she was a very social person, with an easy going attitude and a good sense of humour.

At first Liz appeared positive and confident, albeit a little anxious. Her cognitive impairment was evident even though she had been taking a cognitive enhancer for a number of years. One of the wonderful aspects of the relationship between Liz and Mac was that at no time did he undermine her as a result of cognitive deficits. He gently kept her on track, and redirected the conversation back to the topic when Liz digressed. Not once in the course of our discussions did he let her know when she repeated a question. Even

though she presented with a confident attitude, in reality, Liz lacked self-confidence and often resorted to banter during the conversations. Although she laughed a lot, it was not genuine laughter because she sounded uneasy and unsure.

Confidence is a subjective, emotional state of mind (Sabat, 2001), and being positive implies self-assurance in relation to personal knowledge. Although Liz was naturally assertive, she relied heavily on Mac and often turned to him for confirmation of her spoken words. When asked how she felt about having dementia Liz said: *"You know having this Alzheimer's, it hasn't really worried me because I've got Mac there"* however, that comment was counteracted when in the same conversation she said: *"You know I remember thinking, you know the only thing I want in life is not to have it [Alzheimer's]."* This second remark was contradicted yet again when Liz said: *"You know having this Alzheimer's, it really hasn't worried me. Some of the friends I've got, they know I've got it and they still treat me the same."* Whereupon Mac cynically replied: *"Some of them do"* suggesting that he had noticed a difference in the way some people responded to Liz.

As the discussion progressed I was increasingly aware of Liz's anxiety. At first I thought it was because of the questions I was asking but Liz assured me they were not a problem. Nevertheless, she continued to fidget with her hands, change the topic of conversation several times, and offer cups of tea. This edited version (Appendix T for full excerpt) of the flow of conversation sheds light on the cause of Liz's discomfort:

Grace: *Have you any thoughts as to what has made you jittery Liz? What are you concerned about?*

Liz: *It was all just everything combined you know, ... I don't know why.*

Grace: *Do you feel a bit anxious?*

Liz: *Yes, yes.*

Grace: *Is it because I'm asking you questions?*

Liz: *No, no. It's been, you know, this morning. I woke up a bit, do you think that Mac?*

Mac: *Yes, you get a little bit, every so often. Actually it wasn't so much earlier this morning, it must have been in the last hour or so, since we came in from mass.*

Grace: *Did Liz know I was coming in that hour?*

Mac: *No, probably not. I didn't mention it this morning.*

Liz: *No, somebody else is coming aren't they?*

Mac: *Oh no, that'd probably be afternoon tea tomorrow. Yes, we were arranging that this morning.*

Liz: *That's right, that's the people. They have been great friends but we don't see a lot of them now do we?*

Grace: *So tell me Liz, do you think that knowing they are coming to visit is a bit of a concern for you. Is that what made you uncomfortable?*

Liz: *Only if he wasn't here.*

I asked Liz if she could sense a difference in the way friends responded to her and she immediately replied: *"Oh yes, I sense it alright."* In my attempt to understand the experience of dementia from the person's point of view, I have come to realise that people with dementia are acutely aware when they are being patronized. This notion was endorsed at the conclusion of the aforementioned conversation when Liz admitted:

Liz: *Yes, I do think those friends are a bit iffy about me now.*

Mac: *Which one? You've never mentioned anything.*

Liz: *No I don't. Well I don't want to give you more worry do I? But it doesn't worry me because I don't need it [them].*

Liz also acknowledged that she does not always tell other people she has dementia: *"Well I don't tell everyone now if they don't know, well only ones that I'd like to know."* I asked why she told some people and not others to which Liz responded: *"I think once they know that you have Alzheimer's they are a little bit like that to you"* (making a face). Interestingly, in her response to the question: *"What would you like people to understand about dementia?"* Liz acknowledged her own prejudice towards people with dementia:

That I'm still me...aw well, I'm not so bad. Nobody wants to have it do they? An' so they are all sort of...I think people are a little bit frightened because they don't know what to expect. They think it's, you're going to be crazy or you know, stupid. Well I always did. You know when I heard someone had Alzheimer's, I'd think 'Oh God' you know?

Challenging stigma

All the participants were aware of the social stigma which surrounds dementia but only two couples felt it was unimportant. Consequently, they disclose the diagnosis when the need arises and in doing so they challenge others to deal with their reality. When the topic came up at one of the focus group discussions Gran and Pop offered the following case in point:

Pop: *The biggest thing is, a lot of people that I hear about haven't made a commitment.*

Grace: *When you say they haven't made a commitment, are you saying that they don't accept that there is a problem?*

Pop: *Yep, either one or both of them.*

Grace: *Do you mean they are in denial?*

Pop: *In denial yes, and in fact we aren't. We've told everyone. The bank ladies are awesome, they know. A lot of people know... it just makes life easier.*

Pop went on to explain the strategy he uses to inform people if a problem develops.

I've got a trick up my sleeve with an Alzheimer's fridge magnet [stating Alzheimer's disease]. If I'm with Gran and something happens, well, I just hold that up behind her and everything is dissolved. People change attitudes wow, like that. Whether they can handle it or walk away, it doesn't matter, the same result is given.... There it is there, you just hold it up like that you know. No, we're not in denial.

A similar tactic is used by Dutch and Moses when they want to inform other people that Dutch has dementia. During the same discussion they reported:

Moses: Well once, several years ago when we went to the States, going through immigration, the two of us went to this immigration officer and I was ordered to go and stand back in the line. I had no option then but Dutch got all befuddled and I eventually had to go and sort things out. Subsequently, I printed a sort of card and Dutch has got a complimentary one... it says 'I have an illness causing memory loss and confusion. Please excuse any unusual behaviour'.

Liz: That's good isn't it?

Moses: That's for him to flash if he needs to.

Grace: Do you use it Dutch?

Moses: Very rarely. A couple of times I've asked him to open it.

Dutch: Yes, especially when we go through customs and things like that.

The decision to tell others seems to be greatly influenced by the knowledge that others may respond negatively. Knowing they (people with dementia) may be seen as different in an undesirable way made most of the participants cautious about whom they tell. Indeed, the following story reveals a positive aspect of not telling others. This took place two years after Greg's diagnosis when the America's Cup yacht races were being held in Auckland.

Fiona: Greg was a navigator... and he sailed in yacht races, as a navigator. In the last Louis Vuitton Cup which was here 4 years ago Greg applied as a volunteer. He didn't tell them of the problems he had but then he came home quite horrified because they had taken him on as a navigator assigned to the committee boat. He said "what am I going to do?" We were going to see Ron Haydn the specialist, and he said "Well it's old knowledge Greg, see how you go with it." Greg never put a foot wrong, in fact one thing you got high praise for.

Greg: In the run up to the races, two race officers in charge did an exercise in course navigation. My job was to check the computer-calculated course, calculate the numbers and place them on the chart. They were saying such and such an' what they were saying was nothing like it should be so I didn't want to say anything because I thought maybe I've got the wrong answer. I did it again and still got the same answer so I told him "what you're getting is not what I'm getting." He came over, had a look and he said "you're right."

When I asked Greg if he ever told them about his health problem he responded with an emphatic "**No.**" However, Fiona revealed:

At the very end we had a final party down there and I spoke to the principal race officer and he said how well Greg did. I let him know then that Greg had a problem. He just looked at me and said "I would never have known." I said "Old knowledge."

One has to wonder if the outcome would have been the same if Greg had disclosed his health condition when registering as a volunteer. According to Fiona, people who knew Greg as a competent sailor noticed a slight difference, mostly with reference to his agility on the boat, but not others. In reflection, Fiona said *"It was wonderful to see Greg come home with a grin on his face every night, it was lovely."* This story clearly shows there is merit in the theory of old knowledge with regard to people with dementia. That is to say, knowledge developed over the lifespan lingers. Nonetheless, old knowledge is not taken into consideration when it comes to driving skills.

Driving with dementia

Once a diagnosis of dementia is confirmed, the New Zealand Transport Agency (2009), expects the diagnosed person to stop driving. The paradox here is that there is no single marker which will determine fitness to drive. To judge all people with Alzheimer's, or similar type diseases by their diagnosis is prejudice. In reality dementia has different manifestations for different people and yet this is not acknowledged nor that ability varies between people. Many people have to give up driving as a result of various medical problems and for some it is a relief. Alternatively, others find it difficult, because driving is often associated with the sense of individuality, independence and status (Man-Son-Hing, Marshall, Molnar, & Wilson, 2007).

At the time of data collection, Mick was still driving. One of his favourite pastimes was to drive into town once a fortnight to a favourite record store and spend an hour or so browsing through old records, looking for *"a bargain."* When asked how he copes with driving, Mick said: *"I have car parking problems, I always forget where I left the car but ... I put a flag on the roof. The parking spot I usually get, I've been parking there for 18 months to 2 years."* Mick admitted that on one occasion, *"I got lost, I ended up over the Harbour Bridge"* when driving to a record fair. Marianne was horrified to learn this because she knew nothing about it: *"How did you get back?"* In response Mick explained: *"I just turned the car around and headed back. Why make it hard?"*

Scott was of a like mind. During a conversation about doing things during the day Scott said: *“Well depends what I want to do like. I might want to go shopping right, so I jump in the car and down to the shop.”* This prompted the question: *“Are you still comfortable driving”* to which he replied:

Oh I’ve no problem with that; I mean I’m very careful yeah, you’ve got to accept that, in my situation you’ve got to. I wouldn’t do it if not. That’s basically the good and the badness of it. That sort of helps me cope.

At the time of this exchange when Scott said *“That sort of helps me cope”* I understood him to mean that being able to get in his car and to go out and do things helped him to retain his self-image as an independent person, thus offsetting negative aspects of living with dementia. As previously mentioned being independent was important to Scott, so being able to drive to the golf course or to the shops on his own sustained a sense of identity.

Nevertheless, Scott’s driving was a cause of concern for Polly who knew that dementia can affect complex skills like perception and judgment. Consequently, she eventually arranged for friends to pick Scott up and take him to golf. When his car had to be serviced Polly suggested it might be a good time to sell it, as an economy measure. Polly reported that Scott agreed without too much of a fuss perhaps signalling his insight to the ‘danger’ of driving with dementia or equally it could have been an indication of change in his level of confidence. Understanding of the implications of his health condition may have influenced Scott’s decision. By agreeing with Polly he avoided assessment of his driving ability.

Overt prejudice

The word prejudice is used here because in exploring this issue with a driving assessor trained in comprehensive driving assessments (usually by computer), I asked about outcomes for people with dementia. In response I was advised that: *“With a diagnosis of Alzheimer’s disease there’s little chance of passing a driving assessment”* (K. Gallagher, [registered driving assessor] personal communication, October 2005). This admission would suggest the outcome is predictable when a diagnosis of dementia is disclosed.

Some of the participants felt that losing the right to drive was one of their greatest hardships. Furthermore, being unable to drive had a considerable impact on their way of life. Greg and Rita expressed their irritation over the loss of freedom:

Greg: *One of the most frustrating things for me is losing my... right to drive a car, very hard. Not that I want to be out in the car every day or every hour of the day, it's just handy to know that if you want to go and do something, you can go and do it. It would leave Fiona free-er too. She has to have me tagging along all the time or I get left behind, amuse yourself, there's not a great deal you can do. You can go for a walk or...*

Rita: *Now that [losing my licence] is terrible, ... my biggest no no... humiliating, I really feel that dreadfully. I like my independence and I miss that... I used to say I love my own company every now and again. To go independently and do the sort of shopping that I want to do you know specifically. And so when you can't do that, not that Bernard would ever try to encroach or be too heavy, I would just have to say to him you know, sort of go somewhere and just leave me, but it's not the same you know. You just want to feel the freedom. The fact that I might conk out is scary but I might not conk out too. You know I feel I have the ability.*

Rita's reference to conking out relates to the fact that she lost consciousness on two occasions (in her own home). Despite investigations, the blackouts were unexplained. By themselves, these would prevent Rita from driving for a period of time but the diagnosis of dementia automatically prohibited her from driving ever again. From Rita's point of view, the loss of the right to drive was yet another way in which an important aspect of her identity, one which she regards as central to her sense of self, is diminished.

Gran had yet another story of how being "labeled" with Alzheimer's very quickly put an end to her driving. Following diagnosis she was contacted by the local police. In recalling the event she showed no ill feeling at being asked to relinquish her driving licence.

Gran: *They asked me if I'd give up my license in case of an accident down here with the school. I said yes, willingly. That's when the cop came up and did the big interview and that with me.*

Pop: *It wasn't pressured.*

Gran: *It was voluntary.*

Pop: *It was, as I say, it might happen it may not. We discussed it between ourselves and because of the school down here, well our decision was that she gave it [driving] up.*

The guidelines produced by Standards New Zealand & Ministry of Health (2005) call for a medical practitioner to assess fitness to drive but, GP's are not usually in a position to assess the driving ability of a person in the early stages of dementia. Nevertheless, if

someone with dementia continues to drive after they have been advised not to, the GP is legally obliged to notify the New Zealand Transport Agency which in turn is required by law to be sure that all drivers are medically fit and able to drive competently and safely. If the person does not stop driving voluntarily, the Director of Land Transport can revoke their licence in the interests of public safety.

There is evidence to suggest that having a diagnosis of dementia is an insufficient reason to stop people in the early stages of dementia from driving. Since the rate and nature of deterioration varies, there is no immediate process of inevitable and global decline (Australian and New Zealand Society for Geriatric Medicine Position Statement No. 11, 2009; Breen, Breen, Moore, Breen, & O'Neill, 2007). Driving involves skills that have been learned over many years and so tasks such as changing gear or braking become automatic. Decline in complex skills such as perception and judgment may, or may not, occur. The time lapse since onset also varies and people differ greatly in abilities and confidence. It can be argued that all of these differences affect driving skills so an all-encompassing policy is a prejudiced response to a diagnosis of dementia. Foucault would argue that taken-for-granted assumptions dictate the driving potential of people with dementia. Through discursive orders and social practices, a structure of domination has been legitimized and given authority.

Subtle prejudice

There is another dimension to this discussion. According to Pop, following a diagnosis of dementia, insurance companies are not obliged to honour their contract following an accident where the driver is found to have cognitive decline:

Pop: *Being diagnosed, that's a written document now, and you know her [Gran] insurance is null and void. Her insurance for travel, everything for insurance is out the door. And because it's a legal document... if you have an accident, or you kill some little child, they will have a look at the records?... Oh yeah, I can drive but as soon as the diagnosis has been tabled, you've got to be very, very careful.*

Fiona: *That's right, there is no insurance. You may have insurance but the moment they know... When Greg had an altercation at the side of the garage with the new car, I rang my insurance company and she said "who was driving?" I said Greg and she said "Well, he's not covered because he's on treatment for dementia and he has recognized dementia which is documented" so that was really a bit frightening.*

Foucault's theory that power is not concentrated in one place nor in the hands of particular people but rather there are a multiplicity of power relations at work at any one time

(Walzer, 1986) is borne out by the aforementioned information. The driving ability of people with dementia is impacted by powerful discourses from public servants, insurance companies whose policies are upheld nationally by service providers, and government agencies such as the Land Transport Safety Authority and Standards New Zealand.

The politics of power

Throughout this chapter my aim has been to present the voices of people with dementia in order to expose, understand, and challenge the influence of power and prejudice in their lives. This would not be complete without comment on the power structures that have their roots in government policies. Farley's (2000) argument that prejudiced attitudes and beliefs have a tendency to favour one group over another, or cause unequal treatment, is borne out by the lack of services available to support people with dementia, especially those with young onset. It is well known that the majority of people living with dementia are cared for in their own home by family/whānau, yet there are few social services to assist them.

Take Ron and Ann's experience as an example. Diagnosed with Alzheimer's disease when he was aged 54, Ron was fortunate in that his employer adapted his responsibilities so that he could continue to work for some time after being diagnosed. When he could no longer cope he retired. In talking about retirement Ron said, *"The days are long when there's nothing to do"* so, because he loves the outdoors, he joined a walking group. *"It was just perfect"* he said. Ann added: *"I felt with me being at work Ron's gonna sit at home and not talk to anyone so for me the principal reason for him joining the group was being able to talk and interact with other people."* However, when Ron stopped driving, transport to and from the group became a problem and he had to give it up. He then started walking on his own, but there was an issue with Ron leaving doors open and the house unlocked. Ann resolved this by getting a locksmith to put automatic locks on the doors. Then it was reported that he stepped out into the road without checking for cars, and when Ron's general practitioner advised him not to go out on his own because it was unsafe, Ron virtually became a prisoner in his own home while Ann was at work.

Ann was very resourceful and made a great effort to *"think outside the square to find meaningful ways for Ron to spend the day while I am at work."* This was particularly challenging because there are few options for people with dementia who are deemed unsafe

to go out on their own. As Ron's condition deteriorated, they were allocated two hours home care per week. Rather than have the caregiver do household tasks, which is the usual brief, Ann asked her to come twice a week for one hour a day and take Ron for a walk. Ann also considered day care, but finding an age appropriate place for Ron proved to be impossible. In addition to home care, Ann was entitled to two weeks' respite care to give her a break from the caring role. While useful to some extent, this approach to dementia care is typical in that it supports the carer's needs rather than meeting those of the person with dementia. Moreover, in Ron and Ann's case, respite care was inappropriate because Ron wanted to stay in his own home where he felt safe and secure. After one sojourn in a care facility he refused to go back.

Another insight into the lack of government policies and service provision comes from Polly. Initially, she had hoped the Needs Assessment for Social Care (NASC) team would have ideas for daily activities that would engage Scott because brochures in the gerontologist's office suggested that a referral to the NASC team was appropriate. When a referral was not forthcoming, Polly asked for one, and she was both surprised and disappointed to be informed that it was too soon for a needs assessment; they hadn't reached that stage yet. At the time Polly was shocked, she knew nothing about an eligibility criterion around stages of cognitive decline; rather she expected help from health service providers whom she assumed would have knowledge and experience of Scott's needs.

Foucault's attention to the sociohistorical construction of power provides understanding of the way in which services are organized, shaped and provided (Powell & Wahidin, 2006). In this instance, services have been organized, shaped, and positioned through social systems and processes that determine conditions and limit possibilities. The complex relationship between people at the micro level and government policies is, according to Foucault, an exercise of power (Walzer, 1986).

Policy makers

Recent government policies in the United Kingdom, Australia, Canada, and the United States of America have emphasized the need for specialized skills and knowledge in the workforce to coordinate the care of people with dementia. However, no such policy exists here in New Zealand. This is surprising given the principles of the government's Positive

Ageing strategy (Ministry of Social Policy, 2001) focus on empowering people to live independent and healthy lives while positively contributing to society. Policies aimed at promoting healthy ageing, and ageing in place, fail to offer help to people following a diagnosis of dementia, yet being able to function in the community depends largely on the availability of appropriate health services. What is more, health care for people with dementia involves both acute and long-term care services and thus requires health professionals who are knowledgeable about the process of service provision.

More recently, the Ministry of Health has undertaken a consultation process to develop a strategic guidance document for District Health Boards. The intention is to facilitate an integrated approach to mental health issues including dementia. Nonetheless, there is no guarantee legislation will follow. According to Foucault (1990), this is not surprising since “it is the nature of power, especially the kind of power that operates in society, to be repressive” (p. 9). Foucault would argue that progress will be slow, because the ability to speak freely about dementia and fully accept the reality is alien to the events that have evolved over a hundred years.

Furthermore, there is a paucity of health professionals specifically trained in dementia care. Given the increasing proportion of the population affected by dementia, there is a significant lack of undergraduate, postgraduate, and pre-registration education on dementia for health professionals and/or care workers. Many people with good intentions are currently working in the field, but good intentions are not enough. Knowledge and skill are essential to enable people with dementia to stay in their own homes and communities, and to live life to the best of their ability (Powell et al., 2000). Community support services are not well developed in New Zealand (Gee & Davey, 2006).

Policy formation and service provision

Alzheimers New Zealand Inc. is a national support and advocacy organization for people with dementia, their carers, family, whānau, and community. They also provide advice, information and access to local support services. Historically, the organisational focus has been on the needs of carers. More recently, steps have been taken to broaden this vision and some local branches now run day-care centres and monthly activity groups for people with young and/or early onset dementia. The topic of service provision from Alzheimers New

Zealand Inc. came under discussion at one of the focus group meetings following a question from Bernard:

These early activity groups which seem to me, the only thing that these Alzheimer branches do for patients, what is your impression of them?

Gran: *They were alright to start with, but I had a day when Pop had to go out. He went down there and said, would they mind if I came in without him? He was told no. He came out and he was fuming so I went home. I thought I'm not going to go in where I'm not wanted.*

Pop: *This was an outreach in [location]. It so happened that I had another appointment and I thought what am I going to do?... I can't think what it was, but it was important for the time... I thought I'll do the decent thing and go and ask, and even before I finished the answer was no, we're not a babysitting service.*

Gran: *That's why we don't go anymore. Now to me that was wrong, they didn't want me.*

Pop: *I've given a lot of people a tape from America and there's things that have been done worldwide, you know, and why aren't New Zealand Alzheimer's doing it?*

Rita: *Their adopted policy doesn't include that sort of thing.*

Pop: *That's what I'm saying, that's what I'm thinking, we need change... What I'm saying is there's not enough done for people with dementia and you know there ought to be, there's that much opportunity. In that tape, they had a fun run, just like our Round the Bays Run, but it was only for Alzheimer's. Generating money for Alzheimer's people but it brought a lot of people together. It brought a lot of awareness. Hello, people with Alzheimer's can run too, can do things.*

Ann: *So, what you're saying is that people should have a more general understanding of Alzheimer's, of those who suffer with Alzheimer's. Is that what you're saying?*

Pop: *I think without knowing the pros and cons, they are concerned with money, but you don't have to have money to implement the stuff I'm talking about, all you've got to have is a vision. All you've got to have is the right people behind you. Make up a plan, and approach people, approach schools, approach government, approach anyone.*

Polly: *The Alzheimer's Association is not the ones that are involved here. Their role from my experience, and I've been using them for about 10 years, is helping the carers, giving information out to the public, it's nothing to do with looking after the patient. That to me is not their role, it's not part of their charter or whatever. They have started, I'm sure they started about 3 years ago, for the first time, an activity group once a month, or one morning a week, and they have done that. But to me Alzheimer's you know, whatever their charter is, it is not to look after the patient.*

Pop: *Well yeah, that's the feeling we were getting.*

Ann: *That may change.*

Moses: *They are very good at giving information out.*

Ann: *I think it stems from a generation of Alzheimer branches that were set up round the table by carers, that's the history. It's now becoming an organization that wants to provide for people, especially those with early onset, and younger people, and it's taken a generation to make those changes. It's held back really by people who have been on the committees for years and years. They need a broader way of thinking.*

Polly: *It's much easier to give out pamphlets, than think of activity groups.*

Bernard: *Don't assume I can't do anything till I prove I can't.*

Dutch: *Well said.*

Bernard: *If anything this thesis of hers will draw attention to that very fact. That's what I'm hoping anyway.*

Rita: *It's focusing on the person, that's the important part.*

A number of invisible power structures and prejudices are apparent in this dialogue. Farley (2000) classified prejudices, which give rise to power, into three categories. Cognitive prejudice refers to what people believe is true. An example of cognitive prejudice is exemplified in adherence to the belief that nothing can be done to help people with dementia despite current evidence which shows a combination of approaches can be used to support them and help them to retain skills and abilities. Affective prejudice refers to what people like and dislike, for example, affective prejudice in attitudes toward members of particular groups such as an ethnic group, culture, or religion. This may be likened to having an uncertain attitude or pity for people who live with dementia. Conative prejudice refers to how people are inclined to behave. Conative prejudice is regarded as an attitude because people don't act on their feelings. An example of conative prejudice might be found in expressions of what should be done in certain circumstances. For instance, it may be assumed that people with dementia need a secure environment. These three types of prejudice are often inter-related, but one person may not be subject to all. Some might believe people with dementia possess low levels of intelligence, but still treat them normally. Others may patronise them because they are cognitively impaired, never realising that the symptoms differ between people.

All three forms of prejudice are evident in the last excerpt. Cognitive prejudice is clearly evident in the lack of services for people with dementia. Affective prejudice is apparent in the suggestion that some board members are reluctant to embrace a broader vision which focuses on services for people with dementia rather than remaining a carers' support service. Conative prejudice is obvious in the attitude of the person responsible for the outreach group. One can only wonder at the thinking behind the notion of a babysitting service. There is an ethical and intellectual integrity in opposing this type of power and prejudice. That is why Foucault argued that science and/or philosophical grounding should seek to produce a new, more ethical form of reality using imagination, humour, articulate dialogue, disciplined thought, and practical wisdom (Hoy, 1986).

Abuse of power

What would appear to be an abuse of power by a former board member was revealed when Alzheimers New Zealand Inc. rejected a request to write a letter to support a funding application to the Families Commission for this research project. The request was not for funding from Alzheimers New Zealand Inc. per se, the application to the Families Commission was intended to raise awareness of the plight of people with dementia at a national level while facilitating time and space for the researcher to complete the study. The response from Alzheimers New Zealand Inc. claimed the organization did not support research of any kind. This was surprising, and caused me to wonder how the organisation can advance the cause of the people they claim to represent without research evidence to support their goals at policy level.

On hearing of the response from the national board Ann, who is chairperson of a local Alzheimer's board, took umbrage with what she perceived to be "*narrow-mindedness.*" Consequently, she not only wrote a letter of support herself (Appendix U) she put the issue on the agenda for an upcoming national board meeting. In the course of what was reported to be "*a heated discussion*", yet another participant Pat, who is chairperson of another local branch of Alzheimers New Zealand Inc., and therefore also a national board member, suggested referring to the constitution for guidance. As it turned out the constitution states:

3.3 stimulate and promote research in dementia, including treatment and care of people with dementia and disseminate findings (Appendix V).

Despite the clarity of this statement it would seem that some with power in the organization had decided that research should not be supported. This abuse of power clearly discriminated against the historical principles upon which the organization was built. Thus, it can be said that a Foucauldian approach brought the decision to reject the request for support of this research into question. In other words, questioning the decision not to support research put the previously accepted, and taken for granted, dictate under scrutiny and made it contestable. Whereas one could hope that having found support for the research project in the constitution then it would follow that the application to the Families Commission would be endorsed by the Alzheimers New Zealand Inc. In effect, that did not happen because the legal portfolio holder at national level needed time to develop a draft

policy for the board to consider, so that clear guidelines could be put in place to ensure that the objectives of the constitution were met (See Appendix W for further explication of the action research cycle underpinning this account).

Foucault provides further insight into abuses of power by way of his theory on the dynamic interplay between power and knowledge. According to Foucault, knowledge is used to construct discourses that can then be used as a legitimate power to exclude and control (Rouse, 2005). In this instance, although the wording of the constitution is quite straightforward it may become more complicated by new guidelines being set down by the national board of Alzheimers New Zealand Inc. Any future decisions board members are called on to make with regard to research will consequently be influenced by the amended guidelines. Where Foucault questioned how such relations to power can be rationalized, Habermas (1971) argued that changing strategies of power such as this into an equivalent strategy for the sole purpose of clarifying language, prejudices the meaning of the original intention. Furthermore, Habermas would dispute the stance taken by Alzheimers New Zealand Inc. as an example of prejudice which society must rise above precisely because, as a form of power, it is a source of misrepresentation that blocks valid understanding, and thus, action (Howe, 2000).

Action

Greater understanding of the ways in which power influences prejudices in society was key to the generation of action at national and international levels. Here again, my intention was to support and advocate for opportunities for engagement in daily activities for people with dementia. These actions can be linked to what Kemmis (2010a) termed research for praxis. That is to say, it involved “morally informed and committed action” (p.9) by this individual practitioner whose goal was to “help to shape social formations and conditions” (p. 9) for people with dementia.

At national level

Prior to beginning this research project in 2004, I responded to a draft copy of the Health and Disability Sector Standards Residential Services for People with Dementia Audit Workbook Guidelines which had been sent out by Standards New Zealand & Ministry of Health for public comment. The principles set out in the document proposed the adoption of a holistic approach to care, with an emphasis on quality. However, the content of the

workbook was idealistic; there was a clear lack of practical knowledge and understanding of the variables that need to be considered if people are to engage in purposeful activities, regardless of dementia. My response, which was 11 pages long, was based on my experience of applying knowledge of occupation in everyday situations. Not only was it included in the document in its entirety, there followed an invitation to join a committee set up to review the Health and Disability Sector Standards for Community Services for People with Dementia which I did in 2005. The review of this document took 12 months to complete and contained clear recommendations for service delivery from a committee comprised of a multidisciplinary team of health professionals. However, very significantly, the recommendations contained in these documents were not acted upon at a political level to raise standards that service providers would be measured against.

Knowing that policy makers at all levels act on the basis of the information received, I wanted to use the knowledge gained throughout this research project to give emphasis to the connection between participation, occupation, and health. Accordingly, I successfully pursued an invitation to join an interdisciplinary reference group to support the planning, consultation, development and implementation of the Ministry of Health's Mental Health and Addiction of Older People and Dementia Project in 2008. The goal was to develop a strategic guidance document to advise District Health Boards (DHBs) on an integrated approach (across traditional boundaries between older persons, mental health, addictions, disability and chronic conditions) to meeting the mental health and addiction needs of older people, and people of any age who live with dementia. This was motivated by an assumption that the increasing number of older people in society will translate into an increasing number living with dementia.

During the first and second meetings of the reference group I advocated for the inclusion of service users. Some doubted the ability of services users, especially those with dementia, to contribute. Nonetheless, the chairperson listened and by going into the community to personally meet people with dementia and their family/whānau; the range of data collection was broadened to include their perspective. Given the continued invisibility of people with dementia, this was a constructive step towards addressing power inequalities in the relationships between people with dementia and others. It was also a positive step towards eliminating the stigma that is associated with dementia.

To date, outcomes from that project include a decision from the Ministry to set up new advisory positions within DHBs specifically to support people with dementia. A holistic approach to care from an interdisciplinary team is recommended. The service specifications call for experienced clinicians with a professional qualification in health, such as nursing or allied health, and expertise in dementia care to provide consultation, liaison, advice, information and education services, to the community including service users, carers, and other service providers. From a policy point of view, understanding the specific needs and concerns of service users, in particular people with dementia, is a move towards social equality in the distribution of health services.

Further action which evolved from this study gave rise to an opportunity for health professionals and care givers of people with dementia to enhance their skills and knowledge. Late in 2009, I was contacted by Colm Cunningham, Director of Operations at the Dementia Services Development Centre (DSDC), University of Stirling, in Scotland. The DSDC is at the forefront of advances in knowledge that are changing the way people with dementia are supported in the community and in residential care. In Britain, Cunningham is a respected advisor on national and local policy on dementia as well as issues involving ageing populations. He has a proven record in dementia research and authorship in international journals, books and government reports.

Cunningham contacted me to ask if there would be any interest in him coming to New Zealand to share knowledge and experience of working with people with dementia. With help from one of my supervisors, I canvassed key organizations such as the NZ Association of Gerontology, Alzheimers New Zealand Inc., NZ Nurses Organisation, the Ministry of Health seeking sponsors to support such a visit. The tentative plan was to run a seminar featuring Colm and myself, and a workshop facilitated by Colm. The goal of the seminar was to bring together people with dementia and those who support them, to envisage and learn skills that would support a meaningful, engaged lifestyle for people living with dementia in the community.

The workshop had three goals including:

1. Bring together interested parties to discuss the purpose, benefits and practicalities of establishing a *Dementia Services Development Centre* in New Zealand, that would

- partner with Stirling University, and join already established centres in Northern Ireland, Holland, and partnerships in Hong Kong, Australia and (soon) in Canada;
2. To forge partnerships between professional associations, service providers, researchers, educators and health professionals to establish the framework of what a centre could be; and
 3. To consider the mechanisms required to drive this initiative forward.

The seminar and the workshop were an outstanding success. Initially, it was anticipated that up to 50 delegates might attend the seminar yet more than 70 people registered. The response to the workshop was less overwhelming; however of the 16 health professionals who attended on the day, an interdisciplinary group of eight is now working towards the development of a New Zealand specific Dementia Centre to promote excellence in dementia care.

More action followed. After the replay of my presentation at the 2010 Alzheimers New Zealand Inc. Conference on national radio's Insight programme, Chris Cooke, a researcher from TVNZ One asked if I would consider taking part in a segment for the SUNDAY programme (Appendix X). Of interest was the fact that I had been instrumental in eliminating the use of antipsychotic drugs to manage the behaviour of people who live with dementia in residential care. I envisaged a rare opportunity to draw attention to prejudices relating to dementia and to present better ways of caring for people with dementia. The programme was based on a change process that I had undertaken in the residential care facility in which I worked. Central to the changes were staff training, which involved teaching staff to see the person and not the disease, increased options for engagement in activities, and modification of the environment.

During the course of these changes and as a result of my studies, I had come across literature warning of the improper use of anti-psychotic drugs. Consequently, I did a mini literature review which set me checking the medications being given to the 30 residents who live in the two dementia units. What I found was that nearly two thirds of them were being given either *Risperidone* or *Quetiapine*, and one man was being given both. In most cases the pharmaceuticals had been prescribed before the person came into care but in some instances anti-psychotics had been given because staff experienced difficulty coping with

unpredictable behaviours. Drawing on evidence of the potentially harmful effects of psychotropic medications on people with dementia, I challenged prescribing practices within the facility. Over the following 12 months anti-psychotic drugs were eliminated, and as a result of using alternative strategies, the residents are more alert and aware of what is going on around them. Further evidence of the positive effect of removing these specific drugs is provided by statistics which show that falls in the unit were reduced by more than 50% in one year. Moreover, not only have these numbers stayed down, but there has also been a decline in behaviour management issues. This information was shared at the Healthcare Providers New Zealand Conference held 11-13 August, 2008 in Auckland. It was a valuable opportunity to inform other service providers of an alternative approach to dementia care. Furthermore, the facility won the Built & Grown Environment Award

The invitation to appear on national television followed a similar presentation at the Alzheimers New Zealand Inc. Conference in May, 2010. The SUNDAY programme aired on 3 October, 2010 (Adams, 2010) and feedback from TVNZ One indicated that interest in the programme was great (Appendix Y). An avalanche of surface mail and emails were received by both the facility and I, and it was reported that the clip is being used for training purposes in other residential facilities (Appendix Z). Moreover, there was international interest in the programme (Appendix AA). In another example of action resulting from this research, I agreed to be interviewed about my work on behalf of people with dementia by reporters from several publications such as *Psychology Aotearoa*, *North & South* magazine, and *Insite* (an aged care magazine). Perhaps acknowledging the degree to which media exposure has challenged societal attitudes to people with dementia and their medical treatment, in January 2011, *North & South* magazine named me winner of the Health & Medicine category of their 2010 New Zealander of the Year awards (Appendix AB).

Additionally, in 2010 I received the New Zealand Association of Occupational Therapists (NZAOT) Frances Rutherford Lecture Award (FRLA) (Appendix AC). The purpose of this prestigious award is to encourage occupational therapists in their professional careers and to give recognition to those who have made a significant contribution in their specialist field of practice. In my case, receipt of the award was reported to be a result of many contributions towards promoting the rights of older people, substantial advances within

practice, particularly in services for people with dementia, knowledge development and dissemination in occupational therapy and occupational science, and for capably raising the profile of occupational therapists in professional and governmental forums. The FRL was presented at the NZAOT biennial academic conference on Wednesday 8th September in Nelson.

The findings of this research project were used to challenge occupational therapists to become proactive agents for change in the health field by supporting people's right to have opportunities to engage in meaningful occupations. It enabled me to reach out to the whole profession and to inform them of the key role occupational therapists have in supporting people with dementia. What is more, it is a sound basis from which to inform others that a social response is needed to alleviate the challenges that beset people with dementia.

At international level

Following my presentations at the seminar facilitated by Cunningham and I, the British College of Occupational Therapy, invited me to be a guest speaker at the DSDC 4th International Conference held in London during October, 2010. My presentation, which was titled: *An occupational approach to change in dementia care* (Appendix AD) focused on the benefits of participation in occupation, in relation to the health of people living with dementia. See Table 7.

At the conclusion of my presentation when the chair asked for questions, Agnes Houston, a delegate who lives with dementia, stood up and congratulated me on capturing the voices of people with dementia so accurately. She went on to say that when she was first diagnosed with Alzheimer's disease, a major concern was how she could go on living her life. She recalled going to see a specialist and saying to him: *"You can take away all the health professionals but I need the occupational therapist. She is the only one who can help me live my life"* (Agnes Houston, personal communication 21 October, 2010). Agnes, who is a member of the Scottish Dementia Working Group run by people with dementia, requested a copy of my presentation so that she could share it with the group. In a later email she stated: *"What I remember was the feeling of, she knows what she is talking about. That's what I want in my care and the word hope kept in my head and my heart"* (Agnes Houston, email communication 20 January, 2011) (Appendix AE).

To further explicate the action cycle at a national and international level a summary is presented in Table 7.

Table 7: Summary of action at national and international level

Person	Reflection	Action	Evaluation
Researcher	Aware of the need to make a difference at policy level	Sought invitation to join an interdisciplinary reference group formed to develop a national strategic guidance document. Advocated for the inclusion of service users.	Outcomes include actions designed to specifically support people with dementia. Reduced power inequality.
Researcher	Educational opportunity for health professionals and carers.	Facilitated dementia specific conference and workshop with overseas expert.	Conference well attended. positive feedback. Dementia research and development group formed.
Researcher	Concerned about drug use in place of work.	Argued for the elimination of antipsychotic drugs in work place.	Residents more alert aware, and able to participate in activities.
Researcher	Invited to showcase work on television	Participated in TVNZ One SUNDAY programme to help educate others about the benefits of eliminating drugs.	Nationwide feedback overwhelmingly positive.
Researcher	Honoured by prestigious national magazine	Awarded New Zealander of the Year for Health & Medicine	Opportunity to challenge attitudes toward dementia.
Researcher	Honoured by peers	Received Frances Rutherford Lecture Award for services to older people and more specifically people with dementia.	Challenging occupational therapists to advocate for the connection between occupation and health.
Researcher	Invited guest speaker at International conference	Addressed delegates at the Dementia Services Development Centre (University of Stirling) London conference (2010)	Raising awareness of the role of occupational therapy in dementia care services.

Prior to attending that particular conference I nominated the team in the dementia unit where I worked, for the *Team of the Year* category in the International Dementia Excellence Awards 2010 organized by the DSDC at the University of Stirling. The awards are intended to acknowledge work to improve the quality of life for people with dementia. According to Jemma Galbraith, (the Conference manager, DSDC) there were in excess of 200 entries. Our team did not win first place in their category, but they received a certificate for being short-listed to the top five (Appendix AF). International recognition such as this is an endorsement of progress directly relating to this research.

Summary

The impact of power and prejudices on the lives of people affected by dementia has been addressed in this chapter. The relationship between power, prejudice, and discourses which serves to suppress the interests of people with dementia have been shown to shape understanding and practice in relation to dementia. This understanding provides a framework for the establishment and acceptance of a social stigma. Since the power structures and prejudices inherent in society are largely unseen, they become an accepted part of the social world for people with dementia and their family/whānau. As a result, prejudice flourishes and, to varying degrees, influences the things people with dementia can do on a daily basis. Overt and subtle prejudices which have roots at national level have been found to underpin the lack of services available to people with dementia.

The various actions resulting from knowledge gained in the process of reaching these findings have also been reported in this chapter. Events have included individual, political, national, and international actions all of which challenged existing prejudices, and promoted a discourse of hope and possibility for people with dementia that is achievable by supporting continued participation in occupation. In the final chapter which follows, the findings are summarized and discussed in relation to occupational science and occupational therapy literature. Choice points for quality are addressed, the study limitations are presented and recommendations targeting policy makers, service providers, practice, education, and future research are outlined.

Chapter Eight

Discussion

“Hope in every sphere of life is a privilege that attaches to action. No action, no hope”

(Peter Levi, 1931-2000)

This quotation from Peter Levi has significance for this study and more importantly for people with dementia. Having hope means anticipating a change related to events or circumstances in life. By itself, hope is not a wellspring for change; some action has to be undertaken. In other words, hope can be passive in the sense of a wish, or active as in putting dreams into a plan of action. For instance, consider a person with dementia who never gives up hope of living a relatively normal lifestyle and with help from family/whānau, plans and achieves a satisfactory outcome. In contrast, consider another person with dementia who simply wishes or prays for a normal life, but without any real hope, or yet another who lives without hope.

When living with dementia in the current social and health care context, having hope is the denial of reality. The demoralizing ways in which people with dementia are perceived, and treated affects their sense of self, how they behave and interact with others, and the things they can and cannot do. This occurs because social attitudes and discourses about dementia shape the daily life of people living with dementia. Action is required to change those attitudes and thereby achieve a different, improved reality for people with dementia. This is pertinent to increased costs in health care and social systems.

The prevalence of dementia in New Zealand is forecast to increase from 1.0% of the population in 2008 to 1.5% by 2026. As there is no cure or long term treatment available to help people currently living with dementia, there is some urgency in finding ways to challenge and thereby change the socially-constructed prejudices that undermine them and thus, their family/whānau. To paraphrase Kemmis (2010a, 2010b), ways of changing historical attitudes need to be found to enable people with dementia to live sustainably. In undertaking this research my goal was to generate knowledge of practical solutions that may assist people who live with dementia to maintain functional abilities by engaging in daily activities. The findings of this study demonstrated that they don't need help with the

‘small stuff’; they can cope with that themselves. It is the hidden stigmata, the socio-political challenges they cannot overcome. Furthermore, the findings highlighted the consequences of doing nothing thus allowing me to actively engage in conversations about what needed to be done. By communicating the findings at conference and other venues my aim was to challenge the adequacy of present understanding, and to change current practice. Kemmis (2010b) argued that such actions are happenings that can undermine the significant influence of history. A change in historical attitudes is necessary to support people with dementia to live well.

In my attempt to be inclusive I started out with the intention of using a participatory action methodology. Essentially, participatory action research assumes that a group of people, with a common problem, come together and plan to generate knowledge and disseminate findings through consciousness raising, social critique, and social change (Kemmis, 2005). The overt aim is to change social structures that are oppressive. Once I understood that my study could not claim to be participatory because the participants did not contribute to the planning, I turned to action research because it offered a way of working collaboratively with participants. In 1988 Kemmis and McTaggart defined action research as:

A form of collective self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out (p. 1).

This definition has been modified with the passage of time so the actions in this study are more congruent with Kemmis’s (2005) later observation that practice “is not guided by *present* or *past* knowledge alone; it is also exploratory and open to self correction in light of changes and in light of what one learns *in* and *through* practice” (p. 407). Furthermore, Kemmis (2005) advocated that prudent researchers need to stay alert (to changing objective circumstances) and flexible (over varying subjective conditions). By remaining vigilant to “whatever might become salient to their reading of themselves, their understandings and their situations” (p. 407), new ideas will ‘almost certainly’ overtake the nature of the original course of action to change how things unfold in a given scenario. Such was the case in this study.

The data generated reciprocally developed insights that I had not expected. For example, I asked participants what they would like to gain from the research and their responses shifted me from functional issues to socio-political issues. Similarly, the participants used knowledge gained during participation in the study to change their own ways of doing things. Kemmis (2010b) endorsed actions such as these when he argued that action research has the potential to achieve agreement among participants about what needs to be done. Furthermore the direction taken is supported by Kemmis and McTaggart's (1988) argument that "the approach to research is only action when it is collaborative though it is important to realize that the action of the group is achieved through critically examined action of individual group members" (p. 5).

Eventually the data drove the connections to philosophy. Kögler's version of critical hermeneutics, which brings together the work of Gadamer, Habermas, and Foucault opened up a way for me to integrate philosophy with the data and thus to further develop the themes. For instance, Gadamer's insights into ways of being helped to deepen the analysis and shape the first key theme: *'The nature of being in the world with dementia'*. I wanted to show how personal characteristics shape the individual experience of living with dementia. The second theme: *'Difference: A socially constructed context'* was influenced by Habermas who advocated that only when difference is recognized and accepted can social issues, which disadvantage people, be resolved and people emancipated. Using this lens I came to see the socially embedded nature of difference and consequences that derive from this. To put that into context, society has different expectations of younger and/or older people, men and/or women just as different participants have different attitudes and experiences. It is a social issue that crystallized into a key theme. The final theme, *'Prejudice and power'* derives from the work of Michel Foucault who argued that power practices are largely hidden in society, and that became apparent in this study.

Moreover the action that has evolved, and continues to evolve, from this study provides clear indicators of how to support people with dementia in New Zealand to live well. Thus as Kemmis (2010b) argued, these actions are happenings that reject the resolute influence of history by bringing together reflection and action, theory and practice, to reach new understandings of living with dementia.

A critical preunderstanding

This study has shown that for people in the early to mid stages of dementia who live in the community, a relationship exists between their lived experience, discourse, and social practices of prejudice and power. According to Habermas (1984) when structural characteristics such as this prevail in society, they influence socially coordinated actions and consequently, those same structural characteristics are re-established through action. This theory is grounded in social constructionism with the ‘social’ in social constructionism being about the mode of meaning making. Moreover, constructionism embraces a range of meaningful realities. That is to say “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42).

Habermas’ argument that all reality as meaningful reality is socially constructed was based on a similar theory. Thus, in addition to the lived reality, the reality of living with dementia can also be viewed as a social construction. The latter notion provides impetus to change society’s perceptions of dementia. For Habermas (1973), theory is a creation of, and the reason for, human action and as such it is a means of emancipation. Introducing new knowledge into society will open a space for improved understanding that can facilitate change in society’s perception of dementia. The need for change is long overdue since the current understandings of dementia, which influence attitudes towards people with dementia, are historical, and therefore removed from reality. This research has shown that at different times, in different places, people living with dementia will have divergent interpretations of the reality of living with dementia.

Summary of the findings

The participants in this research brought different perspectives. They were married, single, divorced, widowed, employed, retired, homemakers, professionals, tradesmen, wealthy, and/or poor. Of equal importance, each participant had her/his own life history, likes and dislikes, strengths and weaknesses, sensitivities, beliefs, and ideals. These characteristics were all part of the person before s/he was diagnosed with Alzheimer’s or a similar type of disease process, and remain part of the person now that dementia encroaches on her/his relationship with the world. The unique individuality of the person, so valued in the

western world (Kitwood, 1998) should not be overshadowed by the common symptoms of dementia. The recognition of personal characteristics is essential to their ongoing support since others cannot always know traits that have developed over a lifetime, yet that knowledge is crucial to inform judgments being made and actions being taken. The point is, although the participants had many different voices, their experiences and perspectives come together to reveal the nature of challenges when living with dementia in present day society.

Many years ago, John Dewey (1859-1952) observed that “people adopt the values and perspectives of their social groups in such a way that these factors come to shape their views of the world” (cited in Kincheloe & McLaren, 2000, p. 287). The findings in the data chapters confirm the influences of socialisation processes and are also congruent with the existential philosophies espoused by Heidegger and Gadamer. While the inevitability of dementia is the one certain thing for all people who have a disease process which causes the symptoms, it is attitudes that provide a bridge between the positive and negative aspects of the experience of living with dementia.

The significance of attitudes

The central argument arising from findings in this study is the power of personal attitudes. Winston Churchill (1874-1965, cited in Ballon & Skinner, 2008, p. 218) once stated: “attitude is a little thing that makes a big difference.” This study has shown that the personal attitudes of people with dementia shape their reaction to living with dementia. Defined as a pattern of thinking (Mulholland, 2006), personal beliefs and attitudes determine how people feel and thus how they will navigate their social world. Prior to reaching this insight, I assumed that the carer’s attitude was key to enabling people to live positively with dementia.

Another key aspect of the action in this study has shown that the way things are, is open to critical evaluation. By opening communicative spaces in which to explore the aims and values of society this study has stimulated change in the way people with dementia are perceived. The findings reveal that when existing modes of thinking about dementia are challenged, other people are willing to change their attitude. This has great significance for policy makers and health professionals who develop practices for people with dementia.

Transforming attitudes and thereby practices will help to meet the different, and diverse needs of people with dementia.

In the Western world, most of the prevalent attitudes in society impact negatively on people with dementia. They are set apart for reasons such as prejudice, ignorance, and a perceived lack of intellectual capacity, because society does not know how to support them. The widely accepted beliefs (world-views) which shape attitudes towards people with dementia are grounded in the everyday world. Further, these beliefs are created by socially constructed powers that determine ways of thinking about dementia and thus, they influence attitudes in the wider community. From this point of view, attitudes empower and/or disempower through social structures which shape the daily life of people with dementia.

Living with dementia means living with an unrelenting disease process. Every human being has ongoing potential, but following a diagnosis of dementia that potential is undermined because the disease is characterized by increasing dysfunction. The data have shown that many people withdraw from doing things they enjoy following a diagnosis of dementia because cognitive decline, communication deficits, and/or lack of opportunities reduce their choices. Nonetheless, the greatest barrier to participation is discrimination. As with other mental health problems, others in society respond to impaired cognition with low tolerance or poor understanding and this augments the stigma of dementia.

This research has shown that people in the early to mid-stages of dementia living in the community are very aware of the associated stigmas. In interactions with others, including health professionals, many people with dementia believe they are treated as though they are brainless and their future prospects are hopeless. These beliefs have been legitimized by government policies which further serve to depersonalize people with dementia. This attitude actually conflicts with reality because personal characteristics and past experience have been shown to support individuality. Strategies people use to reconcile differences between their personal and social identities include: striving to appear normal by hiding the diagnosis; confronting discrimination; and withdrawing from social activities. While some try to ignore other people's attitude, many internalize the stereotype, and consequently become anxious, depressed, further withdrawn and eventually hopeless.

In reality, dementia does not affect the whole person. For instance, memory affects perception but by itself that does not render the person incapable of doing other things like making decisions and taking part in familiar and unfamiliar activities. While the notion of disability cannot be denied it is important to recognize that people in the early to mid-stages of dementia do retain abilities. The findings of this study report numerous ways in which people with dementia maintain varying levels of engagement and function. However, those abilities will vary among people depending on their personal circumstances and the type of dementia with which they are living. The analysis used in this study shows that people with dementia, despite many ingenious strategies, are powerless recipients of systemic injustice which contributes to social exclusion. Yet when action is taken against prevailing prejudices, people in the community and health professionals are willing to change their attitude.

Comparing the findings to other literature

The abundance of literature on dementia which is available in professional journals, books, current affairs and education programmes, clearly indicates a keen interest from researchers, academics, professional communities, and society at large. In the past, such information went unchallenged because people living with dementia were not consulted. More recently, including people with dementia in research has been recognized as essential to understanding the reality of living with dementia. This study was specifically designed to be inclusive of people with dementia and their family/whānau so that the knowledge gained is grounded in their experience and can justifiably be used to influence practice and promote change.

The findings confirm and complement a number of other studies undertaken by researchers with a similar stance (Dabbs, 1999; Harris & Keady, 2008; Innes, Blackstock, Mason, Smith & Cox, 2005; MacRae, 2007; Reid, Ryan, & Enderby, 2001; Sabat, 2001; Sabat, 2003; Wilkinson, 2002; Wood, 2005). Additionally, the findings validate still more studies that examined the notion of a new culture of care. A vision whereby dialogue, person-centred care, the physical and social environment, and opportunities to engage in daily activities could blend together to create a more positive approach to living with dementia, and thereby give people with dementia an increased sense of hope (Banerjee, 2005; Borell, Lilja, Andersson Svidén, & Sadlo, 2001; Chung, 2004; Dooley & Hinojosa, 2004; Graff et

al., 2008; Mozley, 2001; Öhman, & Nygård, 2005; Zeisal et al., 2003; Zgola, 1999). These findings counteract writers who focus on the negative aspects of dementia and thereby cast doubt on the potential for hope (De Baggio, 2002; Mace & Rabins, 1999; Packer, 2000; Schultz, 2000; Symonds, 1981).

This sense of hopelessness is reflected in reports that indicate some doctors struggle to give a diagnosis of dementia (Iliffe et al., 1999) and the findings of this study echo research undertaken by Pratt and Wilkinson (2001). They explored the ways in which people were told of their diagnosis and stated that participants were affected by medical practices, carers' attitudes, available information, support, and social stigma. Being diagnosed was said to induce a range of feelings including grief, fear, anger, and depression (MacRae, 2007; Wilkinson, 2002). The findings of this research endorse these claims and go on to suggest that participants who were living an active life expressed a more positive attitude than those who were not so actively engaged. In addition, the findings concur with evidence that suggests one intervention alone is not enough; a combination of interventions, care providers, and professionals is essential to offset the debilitating symptoms of dementia (Clare & Woods, 2004; Marshall, 2005; Shenk, 2001; Zeisal, 2005).

A place for occupational therapy

Using occupations to enable people to live with chronic health conditions such as dementia is a strategy well known to occupational therapists. The body of evidence to support the notion that occupational therapy has a positive effect on functional independence and participation in social activities is mounting (Baum, 1995; Dabbs, 1999; Davidson & Bissell, 2005; Dooley & Hinojosa, 2004; Gitlin, et al., 2001; Graff et al., 2008; Hampson, 2009; Lucero, 2000; Nygård & Öhman, 2002). What is more, research done over time by other health disciplines has conclusively established that the level of satisfaction gained from participation in occupations is directly related to a positive attitude and feelings of well-being (Cohen-Mansfield, 2008; Glass et al., 1999; MacRae, 2007; Perkins, 2004; Reid, Ryan, & Enderby, 2001; Taylor, 2007; Sabat, 2003; Snowdon, 2001).

Two significant pieces of research aligned to the findings of this study are presented in articles by Graff et al., (2008), and Graff et al., (2006). It is robustly argued that people in the early to mid-stages of dementia benefit from engaging in daily occupations because

daily functioning is improved, and carer stress is reduced. Although the findings of my present study are comparable to those presented by Graff and colleagues, they also expand on the underlying beliefs. The present study suggests that engaging in occupations has a positive effect on mood, behaviour, health status, and thereby quality of life for people with dementia.

Assuming that participation in occupation influences people's health and well-being, occupational science presents an integrated approach to support the profession of occupational therapy. Using knowledge generated by disciplines such as social psychology, anthropology and evolutionary biology, occupational science highlights the positive aspects of human tenacity, strength, purpose and potential (Yerxa, 1993). Thus, strengthened by occupational science, occupational therapy can bring a fresh perspective to the therapeutic needs of people with dementia and at the same time, enhance understanding of ways to support and care for them and their family/whānau (Wood, 2005). This is endorsed by the NICE-SCIE Guidelines (British Psychological Society & Royal College of Psychiatrists (2007), which state that occupational therapy for people with dementia includes problem-solving strategies, skill training and carer/provider education and training.

Caring

More than half the people living with dementia are cared for by family/whānau (Access Economics Pty Limited, 2008; Banerjee et al., 2003; Dooley & Hinojosa, 2004; Persson & Zingmark, 2006; Schultz, 2000) and this caring role is said to be more difficult and onerous than caring for people with other chronic health issues, however this claim has yet to be established (O'Malley & Croucher, 2005; Ory, et al., 2000). Nevertheless, there is research to confirm the finding that family/whānau relationships, both young and older, are put under increased pressure when dementia is part of the diagnosis (Baker & Robertson, 2008; Persson & Zingmark, 2006; Sabat, 2003).

This assertion is aligned to the findings of this study which indicate that as the disease progresses the lives of people with dementia become entwined in that of the people who care for them and vice versa. For instance, due to the loss of independence, initiative, and participation in daily occupations, sharing social activities becomes the norm. In outlining the caregiving role, a number of researchers have suggested that those who share

occupations, provide a sense of meaning, purpose, and belonging. More specifically, they foster a sense of identity that benefits the health and well-being of both partners (de la Cuesta, 2005; Hasselkus & Murray, 2008; Keady, Woods, Hahn, & Hill, 2004). As with the findings of this study, several other studies found that the outcome is subject to the interplay between several variables including the nature of the dementia, the attitudes of the people involved, and the actions of others (Corcoran, 1994; Graff et al., 2006; Millán-Calenti et al., 2000; Ory et al., 2000; Sabat, 2003). The age of onset is also pertinent to the things people can do, in that people of different ages expect and need to be able to do different things. Continuing to work as opposed to retiring is a case in point.

The difficulty in recognizing differences between young onset and older onset dementia has long been a topic of discussion in which authors noted an unmet need for service planning (Luscombe & Brodaty, 1998; Perkins, 2004; Taylor, 2007; Tindall & Manthorpe, 1997). Although dementia is relatively rare in people under 65 the findings in this study reveal the need for the development of specialist services to offset excess disability and alleviate carer stress. There is a body of writing to support this stance, much of it grounded in the notion that when energy is combined with anger, dissatisfaction, and restlessness, it becomes a challenge that can be extremely difficult to overcome (Barber, 1997; Delaney & Rosenvinge, 1995; Mace & Rabins, 2006; Perkins, 2004; Reed, et al., 2002; Royal College of Psychiatrists, 2000; Sabat, 2001; Shenk, 2001).

Stress

In the literature, caregiver stress is most commonly talked about in relation to the actual provision of care and female caregivers are reported to experience higher levels of stress than their male counterparts (Hooker, Manoogian-O'Dell, Monahan, et al., 2000). In this study, several of the female caregivers reported feeling highly distressed by the fact that their partner had little or nothing to do during the day. An additional worry was related to financial concerns. Recent interest in gendered approaches to caregiving has generated discussion about various aspects of care, including the strategies men adopt to offset the debilitating symptoms of dementia. Consistent with indicators in this study it has been reported that men try to deal with the symptoms in ways that suit their sense of themselves as men (Calasanti & King, 2007).

Medical intervention is commonly used to cope with the stress of caring for someone with declining cognitive abilities. Research concerned with the use of drugs to treat and control the symptoms of dementia is ambiguous (O'Malley & Croucher, 2005). For instance, there is debate about the benefits of cholinesterase inhibitors. Some studies claim they make a difference to cognitive skills, albeit for a short time, while other studies claim they make no difference. According to Trinh, Hoblyn, Mohanty, and Yaffe, (2003), cholinesterase inhibitors can be somewhat supportive of enhanced neuropsychiatric, and functional outcomes for people living with early to mid stages of Alzheimer's disease in the community. They call for future research to focus on how such improvements translate into long-term benefits connected to quality of life, institutionalization, and caregiver burden. Equally, the hope that atypical antipsychotic drugs might play a part in management of non-cognitive aspects of dementia has been thwarted by evidence of over-prescribing, adverse cerebrovascular events, and increased mortality (Ballard et al., 2005; Ballard & Howard, 2006; Banerjee, 2009; British Psychological Society & Royal College of Psychiatrists, 2007). The participants in this study were ambivalent about the use of cholinesterase inhibitors and only one had been prescribed antipsychotics, so in itself, the study has nothing to add to the current debate over the use of drugs.

Social isolation

A longitudinal study carried out by Sabat (2003) is supported by the findings of this study, which indicate that people with dementia become increasingly isolated and removed from their social world, in part because of communication deficits resulting from dementia. When people struggle to express themselves and/or have difficulty keeping up with conversations, they stop trying rather than feel humiliated (Byrne & Orange, 2005). Other researchers have endorsed the finding that the problem of social isolation is compounded by the fact that people with dementia believe their functional and social losses are connected to how other people perceive them (Allan & Killick, 2008; Harris & Keady, 2004; Snyder, 1999).

There is also research to confirm the finding that social isolation is exacerbated by a lack of transport to enable people with dementia to get out and about. This turn of events effectively limits opportunities to connect with others (Borell, et al., 2001; Breen et al., 2007). The problem is compounded when people are reluctant to and/or have no means of

seeking help. Indeed, Breen et al. (2007) warned that a driving licence should not be withdrawn without due consideration being given to people's capacity to drive as the impact may be substantial. Of note, the findings in this study suggest that some of the changes people with dementia experience may, to some extent, align with older age. Exactly what changes are caused by dementia remain to be shown. In relation to that point, Clare (2003b) warned that older people with dementia should not be judged without an understanding of ageing and its psychological and social implications.

There is a great deal of research to support, verify, and even add to the findings of this study yet no current literature was found to contradict the findings directly. This may be linked to the quiet revolution that is now taking place in exploring the experience of living with dementia. This has brought to the fore concepts of person-centred care, dignity, well-being, and quality of life. That is to say, the experience of the person living with dementia is now being investigated and respected alongside that of family/whānau. Consistent with this study, the social construction of understanding dementia highlights the importance of knowing the characteristics and attitudes that shape the individual experience of living with dementia and contextualizes perceptions of health.

The context of health

In an effort to define and understand concepts of health and how each individual concept relates to health, researchers have focused on component parts such as well-being and dignity in relation to the health context (Arino, 2001; Burke, 2004; Christiansen, 1999; Clarke, 2010; DiBartolo, 2006; Gallagher, 2004; Haddock, 1996). Concentrating on parts of the whole diminishes the dynamic nature of concepts such as identity, dignity, and quality of life whereas understanding these dynamics may help not only people with dementia, but older people who live with chronic health conditions, to live more positively. One argument put forward by this research is that supporting people with dementia to participate in valued occupations will enable them to retain a sense of identity, preserve dignity and self respect, thus giving them a sense of hope while promoting health and well-being. The notion of identity is particularly relevant here because the very nature of dementia affects the way people think of themselves as well as the way other people think of them.

Dignity exists when a person sees him/herself as someone who can participate in, and contribute to the community. The need to treat people with dignity and respect is receiving more recognition in ethical debate around the world (Clarke, 2010). Moreover, both dignity and respect feature in national legislation within the field of health care. This stance is endorsed by research which argued that treating people with dementia simply as “one dimensional beings, experiencing only a living death” effectively undermines their potential (Reid, Ryan, & Enderby, 2001, p. 379).

Limitations and strengths

Each philosophical stance brings specific, yet unique, understandings to the research process and so some limitations are likely due to the method itself (Geanellos, 1998). Still, according to Koch (2006), regardless of the research approach used, reflective writing, which is at the core of this study, develops critical analysis thus facilitating new understandings. In this instance, the qualitative approach of critical interpretation provided not only insight and understanding of the experience of 11 people who live with a diagnosis of dementia and 11 people who care for them, but also the forces that shape their daily life. The findings cannot be generalized since there is no ‘one size fits all’ when it comes to living with dementia. Due to the relatively small scale of the study, its New Zealand context, and the recruitment procedures, the findings are specific to the participants’ experiences. Nonetheless, there will be commonalities and shared understandings with others who live with dementia.

The participants in this study who had dementia were in the early to mid-stages and they appeared to be reasonably well supported by at least one family/whānau member. Family support can have a significant impact on the experience of living with dementia therefore it must be acknowledged that the voices of people who do not have that advantage may not be represented. Similarly, all of the participants lived in an urban area of Auckland. The findings may differ if a similar study was done in an inner city or rural area.

All of the participants, with the exception of one, were affiliated with Western European culture. People from Maori and/or Asian culture, who have a different way of life, may have a different experience. Therefore this study does not suggest that their experience would be the same, rather, their views should be captured to broaden understandings.

Similarly, people from a different socio-economic background may have yet another perspective. Just as different participants bring different perspectives, so too, a different researcher, with different pre-understandings, and using a different methodology, may interpret the findings differently. The use of another methodology could increase understandings of a complex problem by capturing different aspects of the experience.

The significant strength of this research is the participants. Engaging people with dementia in research is a relatively new practice and one that is thought to be risky, given their prognosis of cognitive decline. Although only a few of the participants contributed during the data collection stage, many played an important part over a period of three to four years. In the latter stages, the main focus of the participants was to ensure, as much as possible, that the research findings were grounded in the data. Therefore, participant involvement was maintained over time through consultation and collaboration. Involving people with dementia and their family/whānau was essential to ensure their voices are intrinsic to the research findings.

Choice points for quality

Bradbury and Reason (2001) proposed choice points by which to measure the quality of research. The criteria outlined by Bradbury and Reason will be applied to this research to show the rigorous nature of the methods used throughout this study. In this way, I “hope to build a bridge between academic concerns about validity and more reflexively practical questions about the work of action research” (Reason & Bradbury, 2001, p. 343). The headings include: Quality as relational praxis; Quality as reflective-practical outcome; Quality as plurality of knowing; Quality as engaging in significant work; and Emergent inquiry towards enduring consequence. All the questions raised by these headings will be addressed if only to outline why one is more important than another.

1. Quality as relational praxis

The question here is about the quality of relational participation. Was the action research group set up for maximum participation? Were there opportunities to allow all participants to feel free to be fully involved?

In this regard, the issue of congruence between the process and the exploratory nature of the inquiry was such that full participation and authority was not always possible. The participants did not have an opportunity to be part of the initial planning process. Nevertheless, explicit attention was paid to creating opportunities for maximum participation in genuinely democratic discussions. The intention was to produce knowledge that would lead to action to inform and shape the findings. A great deal of time was spent developing the quality of the relationship with participants with a view to building a trusting relationship. This was thought to be an important social interaction especially since the subject matter, dementia, is considered a sensitive topic. During discussions, participation was encouraged in aspects of decision making about themes arising from the data. Full participation was invited during the focus groups on decisions around the key findings.

2. Quality as reflexive-practical outcome

An important question in this category is whether the research is validated by the participants' new ways of acting as a result of the research? Participants should be able to say that engagement in the research process was useful, or they are using what they learned.

Changes in terms of the participants' personal actions were not the ultimate goal of this study rather the aim was to capture the participant's world-view or experience of living with dementia. Nonetheless, knowledge that was of practical use was shared with a view towards improving the participant's sense of self and self-efficacy. The instances of change that did occur have been addressed in the findings.

Recording significant details of the research process in a reflective journal contributed to the quality of the study. To account for my own biases, I situated myself in relation to the research, and presented my pre-understandings in Chapter 1. Bradbury and Reason (2001) acknowledged that it is difficult to claim 'value-free research', since research can never be free of researcher bias, however, they do suggest it is possible to carry it out in a way that provides reliable accounts about a particular subject. They argued that quality is a matter of making visible the process of research undertaken through reflection and reflexivity (Bradbury & Reason, 2001). In this study, the process of reflection is woven into the very core of the research process and informed by critical interpretation which of itself ensures

that I not only have an awareness of my own position in relation to the process of research but that biases are made visible.

3. Quality as plurality of knowing

This question seeks congruence between theories of reality and practice. The selected methods must also be relational and be able to describe a relational world-view. The goal is to provide a systematic way of engaging people on issues of importance, drawing on many ways of knowing in a repetitive fashion. This question is addressed at three levels.

a) Quality through conceptual-theoretical integrity

Concerned with the theoretical integrity of the basis for the research this point relates to making sense of the data. Attempts to theorise must be firmly based in the participant's experience. Theory is used to bring more order to complex phenomena with a goal of prudent description so that it is also of use to the community of inquiry.

A practical concern when gathering data from people with dementia is the stability of their viewpoint and the accuracy of the information. To offset this issue during the course of data collection, engagement with people with dementia was repeated (a minimum of three interviews). The questions asked allowed for repetition and confirmation of issues arising. In addition, family/whānau were deliberately included from the outset as some people with dementia may be prone to confabulation if they cannot remember details. This allowed for verification of the issues that concern people with dementia during discussions, and eased the process of eliciting data that are confirmable and trustworthy from people who may have either/or poor communication and cognitive abilities.

b) Quality through extending our ways of knowing

This is an opportunity for researchers to use alternative epistemologies such as theatre, dance, and song, to present their work.

In conjunction with text incorporating participant narrative, imagery was used in PowerPoint presentations to illustrate and give authenticity and power to the argument presented on behalf of people with dementia at 14 conferences. Following several of those presentations, the interpretation of data was validated by feedback from others who live

with dementia, as well as feedback from delegates who indicated they found the presentation inspiring.

c) Quality through methodological appropriateness

This relies on engaging with others in a systematic inquiry about conclusions drawn in any given conversation.

To ensure I was not just focusing on parts of the data that supported my own ideas during analysis, I frequently reread the transcripts. I repeatedly listened to the discussions captured on tape to hear again the spoken words and in this way tried to ensure that I was not misinterpreting the information. Additionally, the initial grouping of the data into themes was subjected to peer examination by the participants when they came together at a focus group meeting before being re-categorised into broader themes. Initially, all information was shared in writing so the participants could reflect on it before a more in-depth interpretation of themes was discussed. This ongoing audit by the research participants verified the process of the study, and their questions contributed to reflexive analysis during the action reflection cycle. Furthermore, the thematic analysis was discussed on a regular basis with supervisors and as is customary in a learning environment, the preliminary findings were subjected to peer review by students and lecturers at AUT during three research seminars.

4. Quality as engaging in significant work

This deals with the question of inquiring into what is worthy of attention.

There are several reasons for doing this research project, the most important one being to develop improved understanding and hopefully new knowledge of how people living with dementia in the community can be supported to engage in daily activities. The belief that only people who live with the problem can discuss it with authority, including people with dementia themselves, was deemed to be fundamental to capturing reality. It was also a way of avoiding the power inequalities that prevail in some research on and with people with dementia. What is more, when predictions of an increased number of people with dementia is coupled with recent moves in policy and practice towards social inclusion and justice, it was considered necessary to include people with dementia in research that would inform

practice. From that perspective, this study is well grounded in the everyday lives of people who live with dementia.

5. Emergent inquiry towards enduring consequence.

This point considers the long term, evolutionary, and emergent outcomes of the research

Knowledge gained from this study has the potential to inform dialogue at societal, institutional, policy and government levels. Dissemination of the findings will be a source of information that can enlighten policy makers, educators, and health practitioners and through them service providers. In that way, society at large may come to understand that with support, people who live with dementia can be assisted to live life more fully. Consequently, the implications of the findings will be discussed at two levels; personal support for people with dementia and social change processes.

Implications

The essential implication of this research is the significance of hope. This small-scale study which looked for answers to the question of how to assist people with dementia to engage in daily activities, pinpoints the need to give them and their family/whānau a hopeful vision of the future. Clearly people with dementia are not going to return to their previous level of daily functioning, but they can be assisted to function better and to live more fully. It is this contribution to the existing body of knowledge which gives this study significance. The following quote from research participant, Bernard, supports this claim: *“I think occupational therapy might have a wider application rather than the high science of neurological investigation and lab studies. The personal human approach of occupational therapy may in itself be a solution.”*

People need to have hope in life. Frankl (1964) believed that hope is grounded in the innate hold a person has on life specifically, the person's way of being in the world. Furthermore, he advocated that people's attitude to life relies on having hope for the future because, without hope, people have nothing to strive for. That being so, capitalizing on the strengths and capacities of people with dementia has the potential to sustain abilities for longer periods of time thereby offsetting decline.

A way forward

Part of offering hope is having tangible therapies to offer people. An occupational approach to rehabilitation would support people in the early to mid-stages of dementia by helping them to retain essential skills for daily living. Occupational therapists know how to assess functional ability, to identify strengths and possibilities, while allowing for deficits. They know the benefits of active engagement in daily activities. Furthermore, occupational scientists advocate that occupation is not just about doing, being and becoming; it is about belonging and contributing to society. In fact, the WHO's Ottawa Charter of Health Promotion (1986) endorsed the connection between occupation and health when it stated that "health is created and lived by people within the settings of their everyday life" (p. 3). Adding meaningful years to life depends in part on avoiding the attitude that still, to this day, deems people with dementia as incompetent, thereby leaving them without hope for the future. The findings of this study challenge the authenticity of this position. There is no doubt that dementia is a chronic, debilitating disease and although it is not currently curable, with the development of rehabilitation services, dementia could be managed for years, thus allowing the person to live a more meaningful life.

Rehabilitation has various definitions (Marshall, 2005), the common thread between them all being the approach. Put simply, rehabilitation refers to helping people to function better by facilitating participation in meaningful activities and valued social roles. This standpoint is endorsed by Clare and Woods (2004) who stated that the purpose of rehabilitation is to help people accomplish and/or preserve an "optimal level of physical, psychological, and social functioning" (p. 393) following disability resulting from illness or injury. Friedell (2000) went one step further and asked why intensive rehabilitation is readily available to people who sustain a traumatic brain injury and yet it is untried on people with dementia. There is evidence in this study that people living with a diagnosis of dementia benefit from participation in a wide range of meaningful daily activities. In the context of rehabilitation this implies that other people, especially those with young onset dementia, would also benefit from similar opportunities in a community setting.

A good quality rehabilitation programme takes an individual approach to the person at the centre of care, in his/her environment and incorporates activities planned to meet social and emotional needs, strengths and limitations (British Psychological Society & Royal College

of Psychiatrists, 2007). The approach would be no different for people with dementia. As the ability to engage in one activity declines, that activity could be replaced by another less demanding one to maintain engagement. As long as new interests are made available and people are prepared to try, this approach could continue indefinitely thus giving people with dementia an opportunity to challenge the disease process.

Offering people with dementia a programme of daily activities in which they are supported to participate will enable them to feel competent. Engaging people in meaningful activities would allow them to leave behind the anxiety and uncertainty associated with cognitive decline because connecting with others through normal daily activities is reassuring. Here again Bernard, a participant who believes it is important to keep active, shares his thoughts: *"I think stimulation is crucial, everyone responds to stimulation."* This idea is aligned to the recommendations found in the NICE-SCIE guidelines (British Psychological Society & Royal College of Psychiatrists, 2007) designed to support people with dementia. Those recommendations advocated for people with dementia to maintain cognitive skills, mobility and independence in wider activities of daily living. Enabling people with dementia to participate in daily activities will ultimately uphold their confidence and sense of security.

Confidence is a state of being that would support people with dementia and help to emancipate them. Enabling people with dementia to feel secure and self confident would help to reduce worries and apprehensions, but they need support to stand up for their rights. Most people have a horror of opposing a dominant group, largely because they imagine the group knows best (Stangroom & Garvey, 2005). This assumption may be challenged if people were to think logically about what is being said. Socrates (470-399 BC) claimed that the path to self-confidence is simply confidence in personal beliefs. He advocated that people should not be swayed by the opinions of others and in saying that, he likened people to sheep, inasmuch as most passively follow the leader. Furthermore, Socrates argued that society tends to trust people in authority because most people assume others, particularly leaders, know what they are talking about (Stangroom & Garvey, 2005). Today, some would have doubts about trusting those in authority, the point being, people rarely take action to challenge existing power structures (Foucault, 1979; Habermas, 1984; Kögler, 1999).

Future research

Research into the ‘lived’ experience and actions of people with dementia has increased but there is still a need for more detailed study. This research has shown how people from a (comfortable) lower middle and/or working class background in New Zealand engage in daily activities while living with dementia. A similar study with people from a more affluent and/or lower socio-economic background would be an interesting comparison. It might shed a different light on aspects of living with dementia, when financial security and/or independence can facilitate the acquisition of greater support and expertise. Alternatively, chronic financial stresses might present challenges and responses not revealed in this study.

The significance of attitudes was seen to be important in this study. Another suggestion for future research is a study to determine how to go about changing negative attitudes. An attitudinal change by health professionals in practice would help to undermine the attitudes that prevail in society. The findings of such a study may produce evidence as to how prejudices can be challenged and the social stigma reduced. Similarly, an action research project to address the question of what systemic changes are needed in service priorities and delivery would also be of interest.

There are numerous aspects of living with dementia that would benefit from a study exploring the potential of rehabilitation for people with dementia. Applying the findings of this research to investigate the benefits of active participation, coupled with hopeful, enabling attitudes, may produce new knowledge that would inform a new approach to care, one which would enable people with dementia to retain abilities, enhance life satisfaction, and thereby offset decline. A pilot study exploring potential options for community development would be a starting place. This could then be followed up with a longitudinal study to determine outcomes.

The findings of this research could be further complemented by a larger study looking at the occupations of younger people with dementia. A study such as this may help to capture new ideas or options for service provision. Another research project could interview older people about their occupations. Two separate intergenerational studies exploring occupations may add to understandings of the significance of difference between young

and older onset revealed in this study. Similarly, research examining a masculine approach to caregiving may provide support for the insights this study has given which suggest that female caregivers tend to do too much for people with dementia. It could be argued that a study interviewing men in a focus group would reveal more aspects of difference and strategies that are supportive.

It is distinctly possible that the interpretations offered in the findings of this study have the potential to increase understanding of the experience of living with chronic health conditions, especially those characterized by fluctuating cognitive abilities, such as mental health problems. There are numerous aspects of the experience of living with a chronic condition that would benefit from research including people with various types of health issues. For instance, research which focuses on younger people with impaired cognition from other health issues may expose similarities and differences in experience. Ultimately, this may help service providers to offer a greater range of services.

The voice of people with dementia should be integral to all future research projects seeking to advance knowledge of the experience of living with dementia. Giving people with dementia a voice in future studies, and in the dissemination of personal accounts of their stories, is a natural extension of this study that may help with the development and delivery of services.

The question of action

Change is rarely based on scientific evidence alone; rather it is often aligned to public perception (Harris & Keady, 2008). So what needs to happen to bring about change in political, social, and personal perceptions of dementia?

In education

Caring for people with dementia goes beyond family/whānau, or even one specific health profession, therefore all those involved in supporting people with dementia need to develop knowledge and skills that will assist them to deal with the complexities of this health problem. In the first instance, people who are given a diagnosis of dementia should receive education about the disease, what is known and what is not known. For example, it cannot be known if the symptoms will progress consistently on a predictable time schedule, so people should be informed about the uniqueness of the process rather than being left to

make assumptions about their future. At the same time, they are entitled to know about treatment options, and the positive and negative aspects of taking medications. People with dementia also need strategies to offset excess disability and should be encouraged to maintain participation in daily activities.

Furthermore, the findings from this study may be useful to educate family/whānau on how to support participation with a view towards enabling optimum functioning. This can be done by encouraging people with dementia to maintain a level of independence. In other words, rather than take over a given task, let people with dementia do what they can for themselves. Knowledge of what a person can and cannot do is essential to prevent anxiety and frustration. In addition, family/whānau can identify and plan for daily activities that will meet social and emotional needs. Maximizing autonomy and decision-making, and encouraging social interaction will promote a sense of well-being and may help to delay entry into residential care. Keeping people with dementia in a well-known environment with familiar routines enables them to maintain a sense of identity, confidence, and some independence in their life. Education for family/whānau should also include getting financial and legal matters in order, information on service availability, and support groups.

Similarly, non-professionals in support services such as Alzheimers New Zealand Inc. have a responsibility to become better informed, more understanding, and to make more of an effort to know, and work with, people with dementia. Recently, there has been some movement in this direction, but the organization was originally intended to provide support for the carers of people with dementia. An attitudinal change is required at management levels to develop skills among support workers that will enable them to provide effective support systems for the people who are diagnosed with dementia. There is a great need for community-based services that will provide people with dementia opportunities to engage in occupations that give a sense of competence, preserve identity, and maintain dignity while engaging in a relatively satisfying activity. Addressing the needs of people in the early to mid-stages of dementia alongside the needs of their family/whānau will help to empower them by enabling, rather than disabling.

To fully meet the needs of people with dementia it is vital that education curricula within all fields of health and the social sciences incorporate knowledge about dementia into

undergraduate programmes. This study has the potential to make an important contribution to knowledge development as it shows the multifaceted nature of living with dementia and provides insights into issues that should be taken into consideration when providing care services for someone with dementia. For instance, the research emphasizes the importance of knowing the person and engaging in dialogue that will put the person, and not the disease, at the centre of care. People's stories add depth to the scientific knowledge of the pathophysiology and aetiology of diseases that cause dementia. This is knowledge that students in all health programmes take into practice.

In practice

There are several actions to be taken in practice. While medical approaches to dementia have resulted in improved diagnosis, and the neurological consequences of dementia are more clearly understood, it is important to note that the narrow focus of medicine has tended to disregard the person in light of the symptoms. Evidence suggests that practice is variable, because people with dementia are seen to be different, due to the effect of the condition on their mental capacity.

When it comes to diagnosis, provided they want to know, people with dementia should be informed directly. They are entitled to autonomy, and to the information and support they need to exercise their autonomy as much as possible. The benefit of early diagnosis is more widely recognized, so positive interventions would improve future prospects and give people with dementia and their family/whānau hope. To that end, when delivering a diagnosis of dementia, some attempt should be made to engage people in a therapeutic alliance, and to encourage sharing the diagnosis with significant others. The person with dementia should be included as much as possible in any decision-making process, and explanations repeated as required. Likewise, the diagnosis should be discussed, advice on planning for the future given, sources of help and support identified, and written information made available.

Participation in occupations has been shown to be an important way to assist people with dementia to maintain existing abilities with a view towards offsetting decline. From this perspective, health professionals and support workers need to take a rehabilitative approach founded on knowledge of the person. Essentially, this means taking time to get to know the

person and their family/whānau and to establish a trusting relationship. Inherent in this approach is individual personality, life history, concerns, hopes and dreams. Giving people a hopeful vision for the future, one in which they can live a satisfying life will be achieved by supporting day to day problem solving and promoting participation.

Health professionals also need to take a proactive approach towards countering stigmatizing attitudes. In the current health care context, this would necessitate challenging long held assumptions about eligibility for funding, other people's attitudes about the hopelessness of the diagnosis, lack of action in accessing resources that do exist, such as green prescriptions, and demanding reform of services that immediately focus on the caregivers to the exclusion of people with dementia themselves. In acknowledging the influence of stigma, health professionals can encourage people with dementia through knowledge dissemination and skill-building. Making sure the results of research on drugs and activity-focused studies are accessible to people with dementia and their family/whānau is another way in which health professionals can support them.

In clinical practice, occupational therapists have responsibility to move beyond the traditional one-to-one approach, and to promote systemic change in service delivery. In light of the findings in this study, when considering service provision for people with dementia it would be more productive to work with dyads. It is well known that people with dementia depend on their family/whānau for support and using this knowledge is essential for best practice. In consideration of those who did not have opportunities to engage in valued occupations, for example, younger people with dementia, the results of this study provide a platform from which to argue for service provision that includes opportunities to engage in a varied programme of daily activities.

At policy level

From a policy perspective, the availability of appropriate services is important. In New Zealand, the Health of Older People Strategy (Ministry of Health, 2002) was designed to support the Positive Ageing Strategy (Ministry of Social Policy, 2001) with a vision that “older people participate to their fullest ability in decisions about their health and wellbeing [sic] and in family/whānau and community life. They are supported in this by co-ordinated

and responsive health and disability support programmes” (Ministry of Health, 2002, p. 1). A number of strategies have been put forward by the New Zealand government over the last 10-15 years with a view towards improving the quality of health services for both young and older people living with chronic conditions. These include:

- Blueprint for Mental Health Services in New Zealand: How things need to be (Mental Health Commission, 1998).
- The New Zealand Health Strategy (Ministry of Health, 2000).
- The New Zealand Disability Strategy: Making a world of difference – Whakanui Oranga (Ministry for Disability Issues, 2001).
- Te Tāhuhu – Improving Mental Health 2005–2015: The Second New Zealand Mental Health and Addiction Plan (Ministry of Health, 2005).
- Te Puāwaiwhero: The Second Māori Mental Health and Addiction National Strategic Framework 2008–2015 (Ministry of Health, 2008).

These documents placed people at the centre of the care model, and called for the development of an integrated continuum of care across a variety of settings, including hospitals, residential aged care services, primary health care services, community health services and disability support services. Furthermore, the documents identified the need for significant change in the way services are provided, and several set out a framework for implementing those changes.

Nonetheless, the gap that exists between the Ministry of Health recommendations and actual service provision persists, despite the recommendations outlined in these policy statements (Melding, 2005). The findings of this research project call for a health and service provision workforce to be developed to help people living with cognitive decline and thereby assist family/whānau. It stands to reason that supporting people with dementia will reduce the challenges faced by their family/whānau. People with dementia want to live life to the best of their ability for as long as possible and so while cognitive abilities remain intact they naturally want to do the normal everyday things that other people do to enjoy life. The WHO (1986) supported this goal: “Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential” (p. 1).

The latest policy document from the New Zealand government, Dementia Services and Mental Health and Addiction Services for Older People, has a clear focus on services to support people with dementia and their family by creating integrated family health centres

(Ministry of Health, 2010). “Better, sooner, more convenient health care” (Ministry of Health, 2010, p. 8) is a Government priority, and significant changes to primary health care structures are reported to be underway. The document is designed to assist District Health Boards and the Ministry of Health to eliminate challenges routinely faced by older people who use mental health, addictions, disability and chronic condition services. It remains to be seen if the recommendations are put into action.

At a societal level

The provision of services designed to enable people with dementia to remain in their own home and to engage in a range of daily activities would mitigate the impact of dementia, while supporting family/whānau and potentially delaying the need for institutionalization. Accomplishing this requires a radical overhaul of societal attitudes towards dementia. It requires a refocusing of support services to engage people with dementia in everyday activities, assist them as they navigate societal attitudes, and bring them into partnership in designing services that address their needs. To achieve this we need community development interventions, we need to challenge stigmatising attitudes, we need to work with community partners to educate and prepare people who offer services in the community - gyms, social groups, clubs - to be able to recognize and respond to the needs of people with dementia.

Powered by fast changing technology, news media plays a key role in influencing public attitudes. With its vast reach, the news media is one of the most powerful forces on earth today and can, constructively or destructively, shape the way people think (Habermas, 1984; Thornham, Basset, & Marris, 2009). For that reason, the news media is an amazing force to inform society at large about dementia and to bridge gaps in knowledge by helping to shift rigid societal attitudes that maintain barriers to understanding the reality of dementia. The media has a special regulator role in a democracy. Nothing is more central to this idea than giving voice to all segments of the population. The way in which people with dementia are set apart, and their cognitive decline highlighted, has become accepted in ways that do not apply to people with physical decline. In New Zealand, the media has played a pivotal role in helping to change social perceptions of people living with mental health issues. As a broader social responsibility, the Ministry of Health could take a similar approach and use mainstream coverage to educate society about the potential for living a

meaningful life with a diagnosis of dementia. This would go some way towards reducing the social stigma that prevails in society.

Conclusion

To conclude the argument developed by this research, I refer to Kurt Lewin's analogy between life forces and a river (cited in Cartwright, 1952). Just as the shape of a river influences the direction and pace of the flow of water, so does the social group determine the current of life. The water, which is the river itself, represents people with dementia. The bed and the banks of the river represent other people's understandings and thus shape the way the river will run. The pace of the river is influenced by the lie of the land and the obstacles therein, meaning other forces affect the tempo of the river. The reason this image best captures the reality of people with dementia is that while the water is the river, it is the bed of the river which supports the flow of the water, the banks of the river contain and direct the water, but it is force which energizes the river.

Equally, water has a life and energy of its own, and while the river naturally flows in one direction, depending on the lie of the land the water may meander slowly and leave stagnant pools in some places or it may tumble over stones, crash into rocks and boulders with an ever increasing ripple effect. This action affects the bed, the banks, and force of the river. The interdependence of the bed, the flow, and the force of the river are inescapable, intimate, dynamic, and elusive. Similarly, an interdependent relationship exists between people with dementia, family/whānau, social practices, occupations, and health. The relationship is one of constant interplay and tension that will only change if one or all of the elements generate action.

Tread softly ... For you tread on my life (Michael King, 1945-2004). This quote from King is used to remind us to tread softly on the lives of people with dementia. Water has the power to smooth the way and/or to push obstacles out of the way thus changing the bed of the stream (by wearing it away gradually or tumultuously, See Table 8). In the same way, researchers and practitioners like myself, who recognize the injustices experienced by people with dementia, have a responsibility to stimulate social change, with a view towards reforming health care services and/or other forms of service provision so that people with dementia can live well.

Table 8: Daily life forces: An example of the ways in which social practices shape understanding in relation to dementia.

An interdependent relationship exists between people with dementia, family/whānau, other people, discourse, social practices, and attitudes. The relationship is one of constant interplay and tension that will only change if one or all of the elements generate action. The correlation between the everyday world and its associated processes of socialization, particularly practices of power and domination has significance for people with dementia.

Practices: The everyday world

- The water which is the river itself represents people with dementia.
- The water has a life of its own which influences the direction and pace of the flow of the river, just as people shape their life course.
- The bed and the banks of the river shape the course of the river just as social groups influence the way of life.



Conditions: Discourse and social practices shape attitudes



- The source and force of the water controls and constitutes the river.
- The pace of the river is influenced by the lie of the land and the obstacles therein, meaning internal and external forces affect the tempo of the river.
- Water may be the river, but it is the bed of the river which supports the water, the banks of the river contain and direct the water, and force energizes the river.

Understandings: Structures of power and dominance

- While the river naturally flows in one direction, depending on the structure of the land the water may meander slowly and leave stagnant pools in some places or it may tumble over stones, crash into rocks and boulders with an ever increasing ripple effect. This action affects the bed, the banks, and force of the river. The interdependence of the bed, the flow, and the force of the river are inescapable, intimate, dynamic, and elusive.



End Note

On the morning of Monday 18 May, 2009 I was contacted by a staff member from a branch of Alzheimers New Zealand Inc. who wanted to know if I knew what was happening with Dutch and Moses. Initially I was unsure what the person on the other end of the phone was talking about and in my mind I quickly went back to the last time I had spoken with Moses on the phone, about two weeks previously. The purpose of that call was simply to clarify a point in the data and to reassure Dutch and Moses that the study was progressing but the write-up was taking longer than expected. Towards the end of the conversation I remember vaguely thinking that Moses' voice sounded a little flat but since he had expressed concern over finding someone to care for Dutch while he went to have some tests done, I assumed that was the cause.

Given the extraordinariness of the call I was immediately concerned. I asked the staff member why she wanted to know. She advised that Dutch and Moses house was cordoned off by the police and no-one knew why. I did not ask how she had come by the information as the news came as something of a shock. I was alarmed and immediately imagined the worst. When I said I knew nothing of what was going on, the caller said someone from their office would probably drive by to see if they could learn anything further. The caller went on to say that staff at the organisation "had a lot of input in recent weeks" thus indicating that the concern was reciprocal. Before ending the call it was agreed that if either party was able to elicit any further news the other would be informed.

Later that morning the same staff member rang back to advise that indications were, that one person was deceased and the other had been taken to hospital. No other information was available. Speaking personally, although I was deeply saddened and shocked by this news I was not entirely surprised although I cannot say why. I can only surmise that I have read enough, and I know from personal experience, that life changes for people with dementia and those who care for them. I am very aware of the sense of hopelessness that exists when looking to the future. Although Dutch and Moses seemed to be coping well the last time I saw them at a focus group meeting in November 2007, I had not forgotten their concerns about what the future would hold.

For the remainder of the day I listened to the news on the radio, and watched the news on the television, to no avail. With some trepidation I rang Auckland City Hospital about 5pm because although I did not want to appear to be prying, I was concerned. This tragedy was dominating my thinking and I wanted to know if the information I had been given was correct and who had been admitted to hospital. I was advised that Moses had been admitted to the Fraser McDonald (acute mental health) unit. The telephonist put me through and when I explained who I was, and the reason for my call, I learned that Moses was physically alright despite shattered facial bones and bruises to the left side of his body. He was also reported to be very, very distressed.

I rang one of my research supervisors to report the turn of events. By this time my imagination was working overtime and I was worried. Having reflected on some of the information shared in the course of collecting data for the purposes of the research project I remembered Moses expressing concern for Dutch if anything should happen to him. In fact, it was during data collection that both Dutch and Moses told me that they had made a living will in 1992 or 93 and that they updated it regularly. They were quite open in talking about death and assured me they had everything under control. Further, they had made all their funeral arrangements including details of how they wanted the service conducted, what songs were to be sung, and they had legally appointed a friend as Power of Attorney.

Moses had told me he had specifically built four stone cubby holes into the foundations of their home to safeguard important information and personal papers. His theory was, in the event of a fire, even if the house burned down, their valuables and private papers would be safe. This was typical of Moses who had previously impressed me with other stories of his meticulous attention to detail. Now, stirred by these memories, my thoughts were leaping to unsubstantiated conclusions. Towards the end of the conversation with my research supervisor, I was advised that she would inform staff in the legal department at the University. She was concerned about lawful aspects of the situation and police involvement.

The following morning I rang the branch office of Alzheimer's New Zealand as promised to share the knowledge I had gained. They seemed to appreciate the update as they had not heard anything more. Further to the conversation with my supervisor, I then went back

through the data looking for any mention of suicide but there was none. Later that day I rang the hospital again, I was still trying to process the incident and to clarify my thinking around what could have happened. I also wanted to know how Moses was coping because I felt sure he would be distraught. On being asked to identify myself I was surprised to find the person I was talking too already knew of me. She informed me that Moses had been talking about me and then asked if I wanted to speak to him. I was unsure because I didn't know what to say. Over the phone I could hear the person I now know to be a caregiver telling Moses there was a phone call for him. He asked who it was and the caregiver replied "it's the researcher." "Who" said Moses, "the researcher" whereupon she came back on the line and asked for my name again. "It's Grace O'Sullivan" said the caregiver. "Oh, I'll talk to her" said Moses. "Yes, I thought you would" said the caregiver.

Initially, when he answered the phone Moses wanted to know how I knew where he was. I explained about the call from Alzheimer's New Zealand and my subsequent concern. He then stated that he was pleased to hear from me and thanked me for calling. He had no qualms about sharing his version of what had occurred the day before and immediately launched into his story. Apparently Dutch had been in respite care the previous week and although he said it was okay; on coming home he told Moses he had had enough, he didn't want to go on living any longer. According to Moses, he discouraged such talk and instead asked Dutch to think about what he was saying. When Dutch repeated the statement the following morning Moses said he accepted Dutch's decision. Whether this was the first time they had come to this agreement I do not know. What I do know is that Moses said he finalized a few affairs around the house before he and Dutch took an overdose of drugs. Moses was very matter of fact in his interpretation.

Very important from my perspective was the realization that I did not want to judge the circumstances of this situation. Having no experience of dealing with something like this I felt inadequate and was unsure what to say or do. I did not consider myself a friend however, I had established an easy rapport with these two people and they had been extremely supportive of my research. I decided to go and visit Moses in the unit because it felt like the right thing to do. I rang beforehand to make sure it would be convenient and Moses seemed pleased by the prospect. Surprisingly, when I identified myself on arrival at the Fraser McDonald unit it seemed as if all the staff in the office turned to look at me, in

fact one person was pointedly staring. Before being escorted to see Moses I had to leave my bag in the office along with the bottle of apple juice I had taken for him. People confined to the unit are not allowed glass bottles because they can be used as a weapon.

Another friend had also called to visit Moses but I was made very welcome and after thanking me for coming, the first thing Moses said was “we are so sorry we have let you down.” By ‘we’ I assumed he meant Dutch and himself. Moses immediately expressed concern for my research project and the potential side effects this incident may have. I reassured him that given the circumstances, the research was not a priority, I had come to visit because I was concerned for him, not the research. During the 30 minutes or so that I sat with Moses and his friend, a minder was present. Apparently, it is normal practice for everyone confined to the unit to have a ‘one to one’ caregiver. Moses talked again about what had happened. His affect was flat, and he was emotionally labile, but he was still very open about the course of events. The left side of his face and neck was covered in bruises, his skin was varying colours of black, blue, and yellow. While he did not appear to have difficulty talking he did say he was careful because of the broken bones in his face.

During the conversation, Moses informed me that he had been advised to engage a Queens Council to represent him in the event of criminal charges. He talked about Dutch’s upcoming funeral and seemed to accept that he could not attend because he may be unsafe. The suggestion was that he might be attacked. He stated this passively, there was no display of disbelief or outrage. I asked when the funeral was to take place because I would like to attend out of respect for both Dutch and Moses whereupon Moses voiced concern that I would not know anyone. I explained that did not matter as I had no intention of socializing. Moses advised that the funeral was planned for the following week and said he would ask his power of attorney to email the details, which he did. When I got up to leave, Moses walked with me to the door and surprisingly put his arm around my shoulder. He thanked me profusely for the help and support I had given during the course of the research. He said he found the information I had shared extremely helpful to both himself and Dutch. While he made it clear he had no expectations for the future, he invited me to keep in touch, wished me luck, and urged me to get the research finished. Upon asking a caregiver to open the door to let me out he told her “this is the lady who is writing the book all about Alzheimer’s.”

The Lawyer or Director of Governance, and legal advisor to the University, had advised that I should let the police know of the data I had collected for the research. In that way, its existence was openly declared and a copy could be made available if required. For that reason, when I initially arrived I asked the receptionist at the unit if I could speak to someone in charge. At the time the caregiver who had spent the day with Moses was in handover and the person in charge was with another patient so no one was available to speak to me. I explained my reasons for wanting to speak with someone from the appropriate circle of responsibility and she said she would pass the information on so I gave her my card with contact details. While waiting to be escorted in to see Moses, his caregiver appeared and the receptionist asked him to speak with me. Again I explained who I was and what I had been advised to do but the caregiver only wanted to reassure me that Moses was easy to care for. He said he could not help with anything else and so once again I left a card asking that it be given to the person in charge. The staff within the facility seemed to know of my involvement with Moses so if for any reason the police wanted to talk to me they could find me.

When I went to Dutch's funeral, it was apparent that he and Moses were a well known, and much loved couple. They had a very large, eclectic circle of friends who turned out in great numbers for this final celebration of Dutch's life. The various stories related by the celebrant, and other speakers, clearly illustrated that Dutch was a well respected man of high standards. Indeed, he had won awards for lace making and when designing traditional Dutch costumes, he was said to be a perfectionist. He was also a finch breeder and skilled horticulturist. Significantly, all of the friends who spoke, without exception, referred to Dutch's horrific disease. The same speakers also commented on the incredible job Moses had done in supporting and helping Dutch to live with dementia. It was said that they continued living life to the full with a positive approach and a fun loving attitude. When Dutch lost his ability to make lace, a craft he was said to have spent many hours doing, with his usual resourcefulness Moses' found another activity, one within Dutch's ability. In this way, he ensured Dutch maintained participation in a range of daily activities.

Many of their activities in the latter stages were socially oriented, enjoyable, and so they helped Dutch to cope. Dutch's social and communication skills remained intact and this may be why many people doubted the diagnosis of Alzheimer's disease. Only Moses really

knew the tremendous toll the disease had taken on both their lives. In the last phone conversation I had with Moses while he was still in the Fraser McDonald unit he advised that he was going home for a few hours the next day to see how he coped. He talked about having to have someone live with him (a minder if you will) for the foreseeable future. This was a requirement of his discharge from the secure unit at Auckland City Hospital. He broke down when talking about the prospect of life without Dutch but he was more positive when talking about things needing done around the house.

Of concern to AUT was the impact of this event on the study and data. With the benefit of hindsight, and distance from the incident, I can see that it had not adversely affected the research project. Rather it has served to highlight the sense of hopelessness which all too often pervades the lives of people with Alzheimer's or similar type diseases, whether that be the person with the disease, or the person caring for them. This tragedy draws attention to the harsh reality of living with dementia.

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Appendix A

Northern Y Regional Ethics approval (1)



Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

10 October 2005

Ms Grace O'Sullivan
67a Parr Tce
Milford
Auckland.

Dear Grace

Assisting people who live with dementia in the community to engage in daily activities.

Investigators: Grace O'Sullivan

Ethics ref: NTY/05/08/054

Locations: Alzheimers Auckland Inc, North Shore Hospital, Hauraki Medical Centre, Dodson Medical Centre.

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

Approved Documents

Information sheet received 30th Sept 2005

consent form received 30th Sept 2005

Statement by relative/friend/whanau received 30th Sept 2005-10-10

Questionnaire received 28th July 2005

Certification

The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

Accreditation

The Committee involved in the approval of this study is approved by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, March 2002.

Progress Reports

The study is approved until 01/07/2008. The Committee will review the approved application annually and notify the Primary Investigator if it withdraws approval. It is the Primary Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in 10/10/2006. You will be sent a form requesting this information. Please note that failure to complete and return this form may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Requirements for SAE Reporting

The Primary Investigator will inform the Committee as soon as possible of the following:

- Any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason
- all serious adverse events occurring during the study in New Zealand which result in the investigator or sponsor breaking the blinding code at the time of the SAE or which result in hospitalisation or death.
- all serious adverse events occurring during the study worldwide which are considered related to the study medicine.

All SAE reports must be submitted on the standard notification form, be signed by the Primary Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. If the adverse event is local and does not have the sponsor's report attached, an

opinion on whether the event is thought to be related to the study should be given along with any other pertinent information. It is assumed by signing the report, the primary investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

Amendments

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

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

The Primary Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely



Amrita Kuruvilla
Northern Y Ethics Committee Administrator

DDI: 07-8587021

Email: amrita_kuruvilla@moh.govt.nz

Appendix B

Auckland University of Technology Ethics approval



MEMORANDUM

To: Clare Hocking
 From: **Madeline Banda** Executive Secretary, AUTECH
 Date: 21 November 2005
 Subject: Ethics Application Number 05/213 **Assisting people who live with dementia in the community to participate in daily activities.**

Dear Clare

I am pleased to advise that the Auckland University of Technology Ethics Committee (AUTECH) approved your ethics application at their meeting on 14 November 2005. Your application is now approved for a period of three years until 14 November 2008.

I advise that as part of the ethics approval process, you are required to submit to AUTECH the following:

- A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through <http://www.aut.ac.nz/research/ethics>, including a request for extension of the approval if the project will not be completed by the above expiry date;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/research/ethics>. This report is to be submitted either when the approval expires on 14 November 2008 or on completion of the project, whichever comes sooner;

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTECH for approval before that change is implemented.

Please note that AUTECH grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely



Madeline Banda

Executive Secretary

Auckland University of Technology Ethics Committee

Cc: Grace O'Sullivan sullies@xtra.co.nz

Appendix C

Research information sheet



Information Sheet

Assisting People Who Live With Dementia in the Community to Engage in Daily Activities

Name of investigator: *Grace O'Sullivan*
 Phone: 09 410 9541
 Email: sullies@xtra.co.nz

Project supervisor: *Dr Clare Hocking*
 Auckland University of Technology
 Phone: 921 9999 ext. 7120
 Email: clare.hocking@aut.ac.nz

Second supervisor: *Dr Deb Spence*
 Auckland University of Technology
 Phone: 921 9999 ext. 7844
 Email: deb.spence@aut.ac.nz

This study is being done by Grace O'Sullivan who is an occupational therapist studying for a PhD at Auckland University of Technology. The study aims to understand what people who live with dementia and one or more members of their family/whānau do, to get daily activities done. The study will focus on developing practical strategies to assist people to participate in activities of choice. It is hoped that the study will help us better understand how to support people who live with dementia in New Zealand.

Health professionals working in public health services and general practitioners are helping to recruit volunteers. If you and your family / whānau member participate in the study Grace will ask you to take part in discussions and to be observed doing routine daily activities that you find challenging to do, in your own home or a community setting. These routines may exclude personal activities of daily living. This will take between one and three hours, if detailed discussion or observation is required and, may occur up to four or five times over one year. All the discussions will be recorded on a tape recorder. The tape will be transcribed by a typist. Grace may also ask to video you while you show her the challenges you face when doing things. This will be discussed with you and permission will be sought from you beforehand.

Information you provide will not be heard or seen by anyone other than the researcher, a typist and the study supervisors. This includes your name and personal information plus what is recorded on the tape and video. If the data is to be used for any other purpose, appropriate ethical approval will be obtained. Tapes, videos and the written word will be

stored in a locked cabinet. In written documentation another name will be used instead of your real name.

The information gathered will be discussed with you before a detailed description is written up. Your input will be an important part of the process. The findings will be based on these discussions. The results of this study will be included in a written report that Grace submits to the University. The results will also be presented at conferences or published in professional journals. At no time will the researcher reveal the identity of the participants in this study.

We do not expect that there will be any adverse effects from participating in this study. You should feel free to withdraw from this study at any time.

If questions arise during the study, the Health & Disability Advisor is available for advice at 08004ADNET.

We will not pay you, but if for any reason you are required to travel to take part in the study you will receive refreshments and a full reimbursement of travel expenses.

The inclusion criteria will include:

- diagnosis of dementia (including the type) by a geriatrician or appropriately qualified health specialist.
- English as first language.
- person with dementia supported by at least one family member.
- no other acute illnesses requiring urgent medical attention at the time of recruitment.

The exclusion criteria will include:

- diagnosis of clinically significant depression.
- people in the mid to late stages of dementia.
- diagnosis of other potentially life threatening diseases.
- diagnosis of multiple major health issues.

For more information please contact Grace or one of the people listed above.

Appendix D

Auckland District Health Board Ethics approval



6 June 2006

Ms Grace O'Sullivan
67a Parr Tce
Milford
Auckland

Auckland District Health Board
Greenlane Clinical Centre, Green Lane West
Auckland 3, New Zealand
Telephone: 09 638 9909
Website: www.adhb.govt.nz

Service: ADHB Research Office
Office: Level 8, Bldg. 13, GCC
Postal: PB 92189 Auckland
Phone: 630-9943
Ext: 4085, 4077 and 3122
Fax: 630 - 9796 or 4996
Email: JoanD@adhb.govt.nz
Website: www.adhb.govt.nz/RDO

**This is the ADHB Management Approval.
Please keep in your Trial Master File.**

Dear Ms. O'Sullivan,

RE: Research project A+3504 (NTY/05/08/054) Assisting People Who Live With Dementia In The Community To Engage In Daily Activities

We are pleased to advise that the above research project has received ADHB management approval.

This approval is given based on the materials submitted for ADHB management approval. If there are any amendments to be made, it is **important** that you send a copy of the amendments to the Research Office as well as to the Ethics committee.

Please send a copy of your final report to the Research Office (Level 8, Bldg 13, Greenlane Clinical Centre, PB 92189, Auckland) on completion of the project.

Good wishes for your study.

Yours sincerely

**Joan Dodd, RN, BA, DipPrfEthics
Research Co-ordinator
ADHB Research Office**

c.c. Sandi Millner, Service Manager, Older Peoples Health/A+Links
Dr Hilary Birch, Clinical Director, Older Peoples Health/A+Links

Appendix E

Northern Y Regional Ethics approval (2)


Northern Y Regional Ethics Committee

Ministry of Health
 3rd Floor, BNZ Building
 354 Victoria Street
 PO Box 1031
 Hamilton
 Phone (07) 858 7021
 Fax (07) 858 7070

8 June 2006

Ms Grace O'Sullivan
67a Parr Tce
Milford
Auckland.

Dear Grace

Assisting people who live with dementia in the community to engage in daily activities..

Investigators: Grace O'Sullivan

Ethics ref: NTY/05/08/054

Locations: Alzheimers Auckland Inc, North Shore Hospital, Hauraki Medical Centre, Dodson Medical Centre, Alzheimers Counties Manukau Inc, Auckland District Health Board, Age concern - NorthShore.

Thank you for your letter dated 31 May 2006 to the Northern Y Regional Ethics Committee seeking approval to use additional locality organisations to recruit participants for the above study

Your request and the supporting documents were reviewed and approved by the Chairperson of the committee under delegated authority on 6 June 2006. Approval has been given to add the locality organizations as listed below.

1. Alzheimers Counties Manukau Inc.
2. Auckland District Health Board
3. Age Concern – North Shore.

Please contact me in case of any queries.

Yours sincerely

Amrita Kuruvilla
 Northern Y Ethics Committee Administrator

Appendix F

Northern Y Regional Ethics approval (3)

**Health
and
Disability
Ethics
Committees**
29 March 2007

Northern Y Regional Ethics Committee

Ministry of Health
3rd Floor, BNZ Building
354 Victoria Street
PO Box 1031
Hamilton
Phone (07) 858 7021
Fax (07) 858 7070

Ms Grace O'Sullivan
67a Parr Tce
Milford
Auckland.

Dear Grace

Assisting people who live with dementia in the community to engage in daily activities..

Investigators: Grace O'Sullivan

Ethics ref: NTY/05/08/054

Locations: Alzheimers Auckland Inc, North Shore Hospital, Hauraki Medical Centre, Dodson Medical Centre
Alzheimers Counties Manukau Inc, Auckland District Health Board, Age concern - NorthShore.

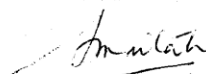
Thank you for your letter dated 25 February 2007 to the Northern Y Regional Ethics Committee seeking approval to address community groups to recruit participants for the above study.

Your request and the supporting documents were reviewed and approved by the Chairperson of the committee under delegated authority. Approval has been given for the following.

-To address community groups such as Rotary and/or Probus and/or others. To attend the group as a speaker and present the research and purpose of the study to the assembled group.

Please contact me in case of any queries.

Yours sincerely



Amrita Kuruvilla
Northern Y Ethics Committee Administrator

Appendix G

Research consent form



Consent Form

Part 1: Researcher Information

Name of Principal Investigator: *Grace O'Sullivan*
 Affiliation: *Auckland University of Technology*
 Contact Information: *0800*
 Email: *sullies@extra.co.nz*

Name of Supervisor: *Clare Hocking, Associate Professor*
 Affiliation: *Faculty of Health and Environmental Science*
Auckland University of Technology, Auckland, NZ
 Contact Information: *64-9-917-9999 ext. 7120*

Name of Co-Supervisor: *Deb Spence*
 Affiliation: *Faculty of Health and Environmental Science*
Auckland University of Technology, Auckland, NZ
 Contact Information: *64-9-917-9999 ext. 7844*

Part 2: Consent of Participant

	Yes	No
Do you understand that you have been asked to be in a research study?		
Have you received and read a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your information?		
Do you agree to have your voice tape-recorded during any discussion groups?		
Do you agree to take part in a video recording while doing an activity?		

Part 3: Signatures

This study was explained to me by: _____

Date: _____

I agree to take part in this study.

Signature of Research Participant 1 _____

Printed Name: _____

Witness (if available): _____

Printed Name: _____

I agree to take part in this study.

Signature of Research Participant 2 _____

Printed Name: _____

Witness (if available): _____

Printed Name: _____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Researcher: _____

Printed Name: _____

* A copy of this consent form must be given to the participant.

Appendix H

Participant initial assessment

Participant Initial Assessment

Name: _____ Address: _____ _____ Phone: _____ Date of Birth: _____ Age: _____ Diagnosis: _____ By whom: _____ When: _____ Medication: _____ _____ Medical history: _____ _____	Co-participant : _____ Address: _____ Relationship: _____ Age: _____ Email: _____ Commitments _____ _____ Concerns: _____ _____ Support: _____ _____ Health issues: _____ _____
Personal Factors (<i>history, qualifications, productivity, spirituality</i>) 	
Issues arising 	
Environmental Factors (<i>attitudinal, physical, socio-cultural</i>) 	

Participation / OccupationSelf Cares (*activities of daily living - domestic, personal*)Leisure (*hobbies, interests, lifestyle*)**Body Structure and Function**Physical / Mental (*communication, mobility, sensory, affect, mood, motivation*)Cognitive (*attention, insight, judgement, memory, orientation, processing*)**Intervention / Goals****Signature/Designation:**

Participant Initial Assessment form

Date:

Created on 1/3/2006 by Grace O'Sullivan (RNZOT)

Appendix I

Participant profile

Participant profile

Name: _____	Date of Birth: _____	Age: _____
Address: _____		
Phone: _____	Email: _____	
Diagnosis: _____ By whom: _____		
When: _____ Medication: _____		
Personal factors (history, qualifications, productivity, spirituality)		
Environmental factors (attitudinal, physical, socio-cultural)		
Participation / Occupation		
Self care (activities of daily living – domestic, ,personal)		
Leisure (hobbies, interests, lifestyle)		
Body Structure and Function		
Physical / mental (affect, communication, mobility, mood, motivation, sensory)		
Cognitive (attention, insight, judgement, memory, orientation, processing)		

Co-Participant profile

Name: _____ Date of birth: _____ Age: _____
Address: _____
Phone: _____ Email: _____
Relationship: _____ Support: _____
Health status: _____
Personal factors (history, qualifications, productivity, spirituality)
Environmental factors (attitudinal, physical, socio-cultural)
Participation / Occupation
Commitments
Leisure (hobbies, interests, lifestyle)
Body structure and function
Physical / mental
Concerns

Signature/Designation: _____ Date: _____

Appendix J

Research questions (1)

PhD research questions

Assisting people who live with dementia in the community to engage in daily activities

Research question: How can people who live with dementia in the community be supported to engage in daily activities?

Introductory question: Tell me about the daily activities you like to do and those it is important for you to do?

Opening question: what did you first notice when you were doing things?

Key questions:

1. Tell me more about doing daily activities.
 - How does your day start?
 - If you want to do something during the day how do you go about it?
 - Who else is involved?
 - What is that like for you?
2. Are there always problems when you try to do things?
 - Are some things easier to do than others?
 - What makes them easier do you think?
3. How long does it take to do things?
 - Does it matter?
4. What do you do that seems to help?
 - Does it work?
5. Is there anything you find really difficult or impossible to do?
 - How important is that?
 - When you can't do things, what happens?
6. Sometimes where we do things is important. Does it make a difference to be in one place or another?
 - Do the problems continue?
 - Are they always the same problems?
7. Do you have any other ideas about what would make it easier for you to do the things you want to do?
 - What else have you tried?

We've talked about a lot of activities today. Are there other things we should have covered?

Thank you for sharing your experiences with me.

Appendix K

Research questions (2)

PhD Research questions x 2

Research question: How can people who live in the community be supported to participate in daily activities?

Rationale: To use knowledge to help others to understand the effects of living with dementia.

Introductory question:

1. How do you spend your day?
2. Tell me about the daily activities you like to do and those it is important for you to do?
 - How do you go about doing what you want to do?
 - Who else is involved?
3. Can you tell me what it is like for you having this disease?
 - What did you first notice going wrong when you were doing things?
4. What effect has the disease had on your lifestyle?
5. How do you go about meeting with family, friends, social groups?
 - Any thoughts on what people need to understand?
 - What would you like them to know?
6. Do you have any hopes, dreams, fears for the future?
 - What do you feel you need?
 - What do you not like about having dementia?
 - What provides you with a purpose, pride, peace, enjoyment?
7. Do you have any thoughts on what type of help you would like available to support you?

Appendix L

A personal example of action cycle at participant level

Action cycle using Lewin's (1948) framework

A personal example of action cycle at participant level

Observation: After the first two or three interviews I realized that my preconceived ideas about problems associated with dementia shaped the direction of data collection. For instance, I started out looking at: *"What kind of challenges are you facing that occupational therapy knowledge can potentially help with?"* In going through the process I came to understand that participants were resourceful in dealing with issues that arise and I needed to acknowledge that (24.4.06).

Reflection: Finding ways to assist people with dementia to retain functional abilities through daily activities is not the problem I had anticipated. Participants have found practical ways of managing day to day issues in the home. Challenges identified in my research log include: stigma, loss of confidence, sense of shame, other people's attitudes and expectations, lack of things to do, lack of external support, no-where to turn to for help, social isolation, no purpose in life, feelings of inferiority, frustration, and sense of hopelessness (31.5.06). Talk to participants about retaining abilities through daily activities in the community, *"What options do they have?"* *"How do they spend the day?"*

Act: Discussed the need for a pro-active approach to offsetting decline, this included the importance of having a balanced lifestyle: *"It's a pleasure to come and talk to you because I'm learning from you. Some people have withdrawn so much and I'm advocating that you really have to try and maintain a balanced lifestyle. I know I said that to you in the beginning and I'm coming to think you've got it worked out. What are your thoughts?"*

Rita: *"oh yes definitely"* (6.7.06).

Realising the significance of engaging in a range of physical, mental, social and spiritual activities. (See Chapter 5: Being and becoming)

Reflection/Evaluation: This helped me to identify a gap between the direction I had been taking and what the participants were experiencing (July/Aug. 06). My focus was shifting, I needed to understand more about the participant's experience. I found myself realising how other people's attitudes and oppressive social forces shaped what people with dementia could and could not do. That came about in various stages:

1. Thinking people need a balanced lifestyle and so I encouraged participants to stay active, to keep doing things they enjoy;
2. Gradually coming to realize that this is difficult for people with dementia because they need support, there are few community services to support them;

3. Those who had a very supportive relationship and maintain a positive attitude seem to manage better than those who have fewer opportunities to stay active.

Modify: Change approach, ask participants what they think the research should explore? What do they think they need? What would they like people to know?

Act: Research questions revised. *“Initially I have come in and asked you questions and sort of taken the research down a track that I wanted to go but my question to you now is: What would you like to come from this research? Have you any thoughts on the direction you would like this research to take? If you can’t answer right now maybe you could think about it because this is about you and not me but we had to start somewhere. So if you could think about what you think you need? What would you like people to know?”*

Response: *“I know what you’re saying, I don’t have any thoughts on it really.”*

Carer [spouse]: *“Well look at it this way what do you feel is lacking? Is there any things that haven’t been put in place or that you’d like to see put in place?”*

Carer response: *“The usual thing that comes up in all the groups that I belong to because I belong to the Alzheimer’s, the Parkinson’s, the specialist Lewy Body carer group, we meet once a month in that group and what usually comes up is the lack of activities and mental stimulation for people in this age group”*(13.12.06).

Other participants validated new directions. There was a consensus of opinion that society needs to understand that people with dementia *“do retain abilities.”* It was agreed that there are few services in place to support people with dementia and their carer, perhaps because *“people really don’t understand the disease [dementia]”* (Jan/Mar. 07).

Reflection/Evaluation: To bring about change, health professionals and society at large need to understand that people with dementia have abilities and they have a right to be supported to engage in life outside the home to help maintain those abilities. There are few options available in the community.

Modify: Talk to participants about using conference presentations to challenge prevailing attitudes and to stimulate change in the way people with dementia are perceived. Move the study from talking about assisting people to live with dementia to promoting the notion of living with dementia as a means of providing some hope for the future.

- Develop skills as a public speaker.

Act: Participants endorsed this change in direction. Abstract submitted to Alzheimer's NZ Conference and accepted.

- Developed conference presentation sent to selected participants for review. Participants feedback suggested: "*Include statistics, tell stories, talk from the heart*" (8.3.07)
- Honed presentation skills.

Evaluate: I developed further insights into the data while writing the presentations. For instance:

- asking people about problems, and what difficulties they've been facing is a pessimistic assumption;
- In the 100 years since Alzheimer's was first identified medical science has actually failed people with dementia. The cause is still poorly understood and there is no long term treatment available to help people;
- The more we do for people with dementia the more we disable them.

Modify: Further conference presentations to be used to educate others and promote the need for "*healthy attitudes*" towards living with dementia. Presentations shared with key participants once they are written up.

Act: Continue to present the preliminary findings at appropriate conferences. Repeating this cycle facilitated sharing the knowledge I was gaining with a view to helping others to think of dementia as a chronic disease that people can live with (See Chapter 5 Action at participant level).

Appendix M

An example of the action cycle in developing the written analysis

Action cycle using Lewin's (1948) framework

An example of the action cycle in developing the written analysis

Observation: Social stigma and other people's attitudes invariably came up as a topic of conversation during almost every meeting with participants. The conflict between participants' perception of other people's assumptions and their own reality is revealing. Comments such as: *"They hear that word dementia and they think only of someone in the very final stages of dementia"* led me to appreciate the connection between ignorance, attitudes, and negative outcomes (13.12.06). Participants' responses included: Refusing to tell others of the diagnosis, withdrawal from social connections, loss of confidence, and a sense of shame.

Reflection: Explore the topic of other people's attitudes in more depth. Important to consider: How do participants respond to social stigmata? What influence does this external force have on their internal beliefs? What strategies are used to offset negativity? (Research journal 23.3.07). Highlight initial codes on the transcripts.

Act: Having identified initial codes such as: stigma, isolation, loss of confidence and loneliness, I shared these with the participants and encouraged them to confront the negative attitudes they encountered in various social contexts. *"We talked about social stigma before and I just wonder how much impact that has on people."*

Dutch: *"Oh I think it has a tremendous one."*

Research question: *"In what way?"*

Mick: *"You don't really know how people will react."*

Research question: *"Do you tell people?"*

Liz/Rita: *"Sometimes, depends."*

Research question: *"On what? If you just tell people you have Alzheimer's then they may be able to understand."*

Mick: *"Hmm"* (June – Oct. 07).

Researcher: *"We've talked about people in society needing a greater understanding and acceptance, but it seems to me that won't happen unless those with Alzheimer's speak about it to people they meet. Despite the fact that the reception at times may not be ideal, you still need to speak about it and that takes courage. I'm wondering if we need to do more of that, so that society can learn and accept and then help. What do you think?"*

General agreement: *"Absolutely, That's right"* (Focus group meeting, 25.11.07)

Through deliberate action the participants may be able to define how negative attitudes affect them in practice.

Reflection/Evaluation: Following this approach I became conscious that I was not the one having to deal with this reality and realised that it is easy to advocate a course of action when not having to undertake the action. Thus I became more aware of the consequences of challenging the status quo, and to be mindful that people with dementia are vulnerable due to their cognitive decline. Being more alert to my own attitudes gave me a deeper understanding of the diversity of attitudes among participants and how these may affect their actions. For instance, Rita's positive attitude reflected her confidence: *"I think the personal attitudes of the person important. You know if you accept it and that's fine, but it doesn't really have to walk with you every minute"* (3.9.07). Scott's determined attitude helped him maintain a sense of optimism: *"I'm doing okay and I hope that will go on"* (14.8.07); whereas Mick's nonchalant attitude immediately raised alarm bells because I thought it made him vulnerable: *"If it's easy I'll go that way"* (12.6.06). I was pleased to learn of a participant's reaction to what he perceived to be a pessimistic attitude from a shop assistant. When the participant explained he had dementia the assistant changed his manner .

Modify: Revisit the participant's interview transcripts looking for similarities and differences regarding attitudes (Aug. – Nov. 07). Revise initial questions and devise a question on challenges in life: *"How do you respond to life's challenges?"* Over time I had come to understand that dementia presents ongoing challenges to which each person will respond differently. Reactions seem to depend on personal characteristics, support systems and/or opportunities.

Act: Developed a category distinguishing personal attitudes, from the attitudes of others. Noted variables in gender attitudes towards a partner with dementia. (Research journal, 27.8.07).

Evaluate: Addressing the question of challenge with participants provided a new insight. Whereas I previously tended to think that living positively with dementia depended, to a large degree, on other people's attitudes, I came to see that I was overlooking the attitudes of the person with dementia (Aug. – Nov. 07). This was an important revelation, and one that has great significance. It made me increasingly aware that a positive attitude from the person with dementia may help to maintain a sense of life satisfaction, self esteem, and self confidence. However, sustaining a positive attitude also depended on the carers attitudes. The power of positive attitudes came together with a more profound understanding of philosophy and alerted me to negativity in the language used in societal dialogue about dementia. I also realized that although some participants spoke positively about living with dementia, in reality, they had unconsciously internalized the negative stereotype. The presumption of disability that pervades social discourse, reflexively affects the attitudes of the person with dementia and their carer.

Modify: Decided to discuss the intermingling of attitudes at the first focus group meeting and with supervisors (Nov. 07). Consider the ways in which diverse attitudes compound the challenges that seem to beset people with dementia.

Act: Focus group participants agreed that a positive attitude from the person with dementia was “*crucial.*”

Research question: *“It seems to me, in the course of our conversations, attitude in almost every instance, both personal and other people’s attitudes has come up and not necessarily because I brought it up. Would anyone like to say more about that?”*

Rita: *“I think it’s tremendously important as far as I’m concerned. I mean eh I know that if I had worried about it, it would have been a different circumstance in my life altogether. But em we spoke about it and I don’t, I just get on with life. But you could make it an issue without really meaning to, I would imagine.”*

Liz: *“I do to.”*

Moses: *“And I think some of it goes back to your attitude earlier in life like if you’ve been a positive person and you have a positive attitude to life then that will help you through this process”* (25.11.07).

Furthermore, they posited that maintaining a “*healthy attitude*” was essential for all concerned to help offset the influence of other people’s attitudes. Supervisors recommended linking these findings to relevant philosophy (May, 2008).

Evaluate: Attitudes pervaded the data in this study to become the overarching theme through a cyclical process. Exploring this theme in relation to the other findings helped to identify the key theme: ‘Personal attitudes’ and strengthen connections to the underpinning critical hermeneutic interpretation (See Chapter 4: An overview of data analysis strategies).

Appendix N

An example from the data (1)

Dolores and Desmond 1½ hours 1st March 2007

Intro As always, both were very welcoming. I am keenly aware that I have to move the study along. To do that I asked Dolores to let me watch as she made coffee. She did not appear to have any concerns about doing this.

Desmond very interested in the idea of attending the Alzheimer's New Zealand Conference in April. Some discussion around the programme, key speakers etc. He seems to be quite enthusiastic.

Obs. Dolores relatively competent in the kitchen. Chatted away quite happily. There was some repetition i.e. getting the sugar out of the pantry, putting it away, and then getting it out again. Serving biscuits even altho' I had said no thank-you x2. Asking Desmond x2 whether tea or coffee when he had quite clearly asked for juice.

Some inefficiency in that Dolores prepared the cup etc. before putting the water on to boil.

In looking for ways to help Dolores maintain her abilities Desmond has expressed an interest in the C.M.O.P. Apparently he has tried to put together a performance measure that for Dolores to track changes. I agreed to come back and help them to simplify the content. I have concerns that Desmond has high expectations. Maybe a hint of frustration - at the increasing challenge to care for Dolores.

Appendix O

An example of research participants in action

Action cycle utilizing Lewin's (1948) framework

An example of research participants in action

Observation: A request for feedback on a presentation for the Alzheimer's New Zealand Conference (2007) elicited a degree of curiosity in the conference proceedings from Bernard:

"Where is the conference? How long is it on for?"

Reflection: Given his desire to learn more about dementia and in particular, to find new ways of helping Rita to offset decline, I thought Bernard may benefit from attending the conference. Discuss at the next meeting. (1 March, 2007)

Act: After giving his opinion on the presentation *"Looks good to me. Some of it a bit academic but I like the bit about dignity, that is so important, and retaining abilities"* Bernard raised the topic of the conference: *"I've been thinking about this conference."* He wanted to know if it was only for academics and/or health professionals. I assured him that people with dementia are encouraged to attend. Furthermore, I informed him that some of the presenters either have dementia or are caring for someone with dementia so: *"It's an opportunity to learn from others."* Knowing he admired Prof. Richard Faull's work I advised Bernard that Prof. Faull was a keynote speaker: *"Yes, I've heard Richard Faull speak, he's very good. A straight talker, tells it like it is."* I also commented that: *"I find they [conferences] can be informative, you probably would too, a valuable opportunity to find out what's going on, especially overseas. They have international speakers from Canada, the US and Australia."* Upon leaving, I encouraged Rita and Bernard to: *"Think about it, I think you would learn from it."*

Evaluate: Bernard obviously interested in the conference but has concerns about costs, travel, and accommodation: *"We'd have to stay over a few nights."* Rita particularly keen to go but that may be more to do with having a holiday: *"We haven't been to Wellington in a long time."* Endurance was also a concern for Bernard: *"Would we have to go to every session? The days are quite long and I don't know..."* His determination to learn may well overcome concerns. (8 March, 2007)

Modify: Take a copy of the conference brochure to the next meeting so they can look at the programme and reflect on the content. Send a link to conference web site by email. (9 March, 2007)

Act: Rita and Bernard attended the Alzheimer's NZ Conference (2007) and were sitting in the front row, nodding enthusiastically, during my presentation. In conversation during the break they

indicated that they: *“are enjoying the conference immensely”* and attended: *“as many presentations as we could”* particularly those given by carers. (27 April, 2007)

Evaluate: Bernard stated: *“That was a tremendous help by the way, thank you. It was an exhausting trip but very worthwhile.”*

Modify: Heeding the call of one presenter who advised: *“Don’t try to care for someone with dementia alone”* Bernard changed his approach: *“Listening to that bloke talking about the impact to his health, trying to cope on his own, I thought right, I’m going to make some changes.”*

Act: Bernard reported: *“We came home and I told the girls they will have to help more. Since we got back we’ve talked about it and they [daughters] come and take Rita out, they go shopping or whatever two and three times a week. We’ve set up a routine, it gives me time on my own, time to relax, to get things done.”* (20 June, 2007)

Evaluate: Question asked at a later date: *“After the conference you said you would include your daughters more, is that still working for you?”* (3 October, 2007)

Bernard: *“That was for my sake that bloke convinced me that was speaking there, I needed some help, so I told the girls that it wasn’t just now for their mother, it was also for me ... two of them can’t help anyway because they are in other parts. The three that can be involved have been involved as much as they can. They do try very much to sustain that regularity, particularly V, comes every Wednesday. So yes, they’ve tried and it’s helped. It’s very good because I never go anywhere or do anything when Rita goes out. I just stay at home but I manage to have time to think, just do things more slowly. I’ve got no other people to think about I can just do or think about what I want to do so I don’t want to go out and have a wild fling, don’t know why I don’t. Don’t think I could but it’s interesting I have no desire to go out at all I just want to stay here and be quiet. Parents don’t want to be beholden to their children but...”*

Question: *“How do you feel about that Rita?”* Rita: *“Oh no, we’ve always had a sense of fun you know and I don’t want that to stop. After all this has happened there’s nothing much I can do about it so let’s get on with living the best we can.”*

Bernard: *“That’s the healthiest attitude I think.”*

Appendix P

Letter from the Director of Mental Health



Office of the Director of Mental Health

133 Molesworth St
P.O. Box 5013
Wellington 6011
New Zealand
Phone (04) 496 2213
Fax (04) 496 2559
www.moh.govt.nz

27 August 2007

Ms Grace O'Sullivan
Doctoral Candidate
School of Occupational Therapy
Auckland University of Technology
Private Bag 92006
AUCKLAND

PP50-01-0

Dear Grace

Thank you for your query regarding dementia.

The definition of 'mental disorder' in the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the Act) is based on symptoms (or phenomena) rather than diagnosis. The actual diagnosis remains relevant in relation to the exclusions in section 4 of the Act. However, none of the section 4 exclusion criteria apply to dementia.

The first limb of the definition of 'mental disorder' in section 2 of the Act is 'an abnormal state of mind, characterized by delusions, or by disorders of mood or perception or volition or cognition....' According to the *Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992*, 'disorder of cognition' clearly covers cognitive changes in dementia and other acquired organic mental disorders (Ministry of Health, 2000, p.14).

The second limb of the definition of 'mental disorder' is that the 'abnormal state of mind' is 'of such a degree that it poses a serious danger to the health or safety of that person or of others; or seriously diminishes the capacity of that person to take care of himself or herself.' If the cognitive changes associated with dementia are of such a degree that the second limb of the definition is satisfied, then dementia will come within the definition of 'mental disorder' in the Act.

Thank you again for your email. I trust that this response is useful.

Yours sincerely

David Chaplow (Dr)
Director of Mental Health

Appendix Q

Abstract for Ageing in New Zealand Conference, 2006

Ageing in New Zealand: Reporting Research Progress Conference

**Te Papa, Wellington
13 November, 2006**

DAILY ACTIVITY, PARTICIPATION, AND PEOPLE WITH DEMENTIA

**Grace O'Sullivan
PhD Candidate
Auckland University of Technology**

Abstract

Background:

There is increasing recognition that a combination of modalities are required to help improve quality of life for people who live with dementia and their family/whānau. Furthermore, international trends indicate growing awareness that people with dementia have an important role to play in identifying their own support needs. These trends may contribute to the Ministry of Health's goal to promote positive ageing by enabling people to live successfully in the community.

Methods:

This presentation focuses on an action research project being undertaken as a PhD thesis in New Zealand. People in the early stage of dementia and a family/whānau member were recruited to work alongside the researcher to understand the difficulties they experience doing daily activities. Data is gathered by interviews and observations.

Findings:

Preliminary insights reveal that individuals and their families struggle to find ways to manage the impact of this debilitating disease. Case examples show that unique and common solutions coexist. With support and encouragement, people are able to problem solve and trust their own initiatives.

Implications:

This study will generate knowledge of ways to assist people with dementia, and their family/whānau to participate in daily activities at home, at work and in the community.

Appendix R

**Abstract for Association of Gerontology /Age Concern
Conference, 2009**

Association of Gerontology & Age Concern NZ Conference

7-9 October, 2009

Exploring the concept of occupational justice for people with dementia

Presenting Author: Grace O'Sullivan

Affiliation: PhD Candidate
AUT University
Auckland
New Zealand

Abstract

This research report, the first of its kind in New Zealand, explores the concept of occupational justice for people with dementia. The notion of occupational justice is about recognizing, and providing for, the occupational needs of people and communities as a step towards healthy living in a fair and just society. Drawing on the findings of an action research project undertaken as a PhD thesis the results provide compelling evidence that participation in occupation plays a vital role in maintaining health, yet social and medical attitudes around the abilities of people with dementia imprisons them with ideas of who they are, and what they can and cannot do.

The research focused on the challenges people with dementia face when they participate in daily activities. To facilitate understanding of the difficulties they experience and how they address those difficulties, people in the early stages of dementia and their carer collaborated with the researcher. Data were gathered by interviews, focus groups, and observations. Underpinning the study is the belief that people with dementia have an important role to play in identifying their own support needs.

Although challenging, the decrease in a person's ability to do things should not be a total loss. This presentation will show that people with dementia who participate in daily activities do retain abilities. The injustice many face is that not all people with dementia have the same opportunities. Their occupations are curtailed by patronizing attitudes, disabling services and medications, and lack of knowledge on how to support them to engage in valued occupations. The lack of opportunity to do things leads to further decline whereas the right kind of doing could be a catalyst, enabling people with dementia to maintain a healthy and satisfying lifestyle. The findings have relevance to family and friends, members of the community, health professionals, and policy makers.

Appendix S

Media coverage

-----Original Message-----

From: One in Five [mailto:OneinFive@radionz.co.nz]

Sent: Tuesday, December 01, 2009 1:48 PM

To: Grace O'Sullivan

Subject: RE: Media coverage at Ageing conference

Hi Grace,

How are you? It seems an age since we met up at the conference in Wellington.

Just to let you know you'll be featuring on One in Five on Sunday evening 20 December, after the 7 pm news on RNZ National 101 FM, and thereafter on the webpage: www.radionz.co.nz/oneinfive

Cheers

Mike Gourley
Producer and Presenter
One in Five
DDI +64 4 474 1714
email: oneinfive@radionz.co.nz

>>> "Grace O'Sullivan" <sullies@xtra.co.nz> 23/09/2009 8:01 p.m. >>>

Hello Mike

Sorry for the delay in responding. According to the Conference programme I am scheduled to present my paper between 10.30 * 12.00 on Wednesday 7 October. Happy to meet with you at more or less any other time that suits you.

Best*

Grace

Grace O'Sullivan MHSc.(OT), NZROT
Doctoral Candidate
School of Occupational Therapy
Auckland University of Technology _____

Private practice: Services for older people

Editor: New Zealand Journal of Occupational Therapy _____

Email: sullies@xtra.co.nz

Phone: 64 9 410 9541

Fax: 64 9 410 9542

Think Green - don't print this email unless you really need to

-----Original Message-----

From: One in Five [mailto:OneinFive@radionz.co.nz]

Sent: Friday, September 18, 2009 11:39 AM

To: sullies@xtra.co.nz

Subject: Media coverage at Ageing conference

Hi there,

I'm the producer and presenter of Radio New Zealand's weekly disability issues programme. As such I'm keen to meet up with you and interview you for the programme.

As I understand it, the conference runs from 7-9 October. I've got time on the 7th and 8th. Would that work for you?

Cheers

Mike Gourley
Producer and Presenter
One in Five
DDI +64 4 474 1714
email: oneinfive@radionz.co.nz

Appendix T

An example from the data (2)

Data

G so R do you have any hopes or dreams or even fears for the future?

R as long as I've got A I don't ... but I would have otherwise dear

G what would you be afraid of R do you think? R well I'm not used to being on my own ... and ah I don't know how would I cope an that type of thing but other than that what would you say

A mm R yeh sometimes I get even today I got a bit jittery but you were there and I knew you were there somewhere I didn't know where he was but I knew he was somewhere around

G have you any thought, what made you jittery R what were you concerned about R uh well it was nothing much, it was all just everything combined you know, sort of the day even now I am laughter I don't know why but would you like a cup of tea

G No thank you not right now do you feel a little bit anxious R yes yes G is it because I'm asking you questions

R... no no no its been you know this morning I sort of woke a bit do think that Mac A yes you get a little bit every so often yeah actually it wasn't so much earlier this morning it must have been the last hour or so R yeh A since we came home from mass

G did R know I was coming in that hour R no it wasn't you A no probably not, I didn't mention it this morning R no but somebody else is coming aren't they A oh no that'd probably be the afternoon tea tomorrow

R oh I see A yes we were arranging that this morning R oh that's right that's the people they have been great friends but we don't see a lot of them now do we they've had their problems to tho' I think most people do don't they

G yes absolutely A there doesn't seem to be anything that sets her off at all she just gets a little bit you know a little bit twitchy I don't know it's hard to explain it R I don't punch him in the nose A no no nothing direct or positive laughter R I just like to know he is somewhere around

G do you think that might be a kind of a fear of the unknown because R yes G because your memory is a little bit flakey and it leaves you a bit uncertain about what the day is going to bring

R yes G or how the day is going to unfold R yes G and that makes you anxious R I think so it probably is although usually if he goes out occasionally I say look I'm alright which I am you know I've got a book sitting there and I turn the TV on if I wish and I'm not I'm perfectly alright aren't I I don't worry

A yes yes good as gold it's like I said to you the other day you know I've never come home and found her anxious when I've come home so no it's rather hard to explain its one of those things

A it's mainly you feel a bit lost because you can't remember something R yes yes A ... she was going to do something but she can't remember what it was

G I imagine that might be a bit frustrating R R yes well it is yeah

A but to go back to your question em you sort of don't worry about the future at all do you we're sort of here and R no A if I was sick and died tomorrow well you'd probably have to go into care R yeah

R and friends like that are a bit well they hang around a bit don't they sometimes
but I think they are a bit conscious of it A well only because we've told them and
probably because you do repeat things fairly regularly I think they've noticed that

A probably just a worry about the future possibly to answer your question there but we
don't even discuss it really G one day at a time R yes yeh

G what about hopes R is there anything you would hope for R not really
just hope to die a good person sometimes like now I feel a bit depressing I could
cry I don't know what it was G maybe it's the rain R the weather G
you see great minds think alike that would depress anyone R miserable out
you know terrible G On a sunny day, it lifts your spirits

R yes yes it does Do you ever get a little bit depressed well not depressed, but you know
down G Oh gosh yes R yes down I think everyone does occasionally A
everybody does R its getting old isn't it you've had a good life of
it dear R you said something about somebody coming round A that's ... not
today R well we haven't seen a lot of them A they used to live next door to us at
the other house they had 8 kids we have 7 15 kids between two houses

G mm that's a lot A we had a lot of fun R that's right we had a lot of
fun R they are spread all over the world now G ... so tell me R do you think
that knowing they were coming to visit was it a bit of a concern for you, made you a little bit
uncomfortable R the only part was if he wasn't here A no this was up at church R
yeh A it was if you go up and spoke to them
R yes I know they weren't well after church

G I just wondered because I don't like to think that it is me making you uncomfortable
R oh no dear, not in the least dear not in the least I've got bad memory A
no no she didn't know you were coming she's alright for people to come ... not
being able to do much about it herself G yeh a bit frustrating A yes frustrating

G I would imagine it worries you a little bit or you're not quite sure what you're worrying
about but the feeling is there R yes that's just it it's a feeling I get a bit
anxious G can you sense that people treat you differently R Oh yes, I sense it alright.
Yes, I do think those friends are a bit iffy about me now.

A Which one? You've never mentioned anything. R no I don't. Well I don't want to
give you more worry do I? But it doesn't worry me because I don't need it. Anyway would you like
a cup of tea or something?

Appendix U

Letter from chairperson of a local branch of Alzheimers NZ

ALZHEIMERS
COUNTIES
MANUKAU
INC



P.O. Box 51-291, Pakuranga,
Manukau City 2140, Auckland.
Phone: 09-576 7776
Fax: 09-576 5891
Freephone: 0800 004 001
Email: info@alzcm.org.nz

21st June 2007

To Whom It May Concern

Research Project – Innovative Solutions to Support People with Dementia & Their Families

Dementia is on the increase and, with the baby boomer population reaching 60, it is imperative that better support services are planned early.

This research is the first in New Zealand, to specifically include people with dementia & their carers and Alzheimers Counties Manukau supports this research project. Research of this nature is very necessary to fully understand the needs of people who live with dementia and their family/whānau.

We have provided Grace with introductions to people with dementia & their families. It is imperative that the needs of these people are included in any research which looks at improving their quality of life and therefore help them to stay at home for longer. Their opinions must be at the forefront of any future planning.

This research also looks at the impact of this diagnosis as it relates to the primary carer and takes into account the significant difficulties being faced by that person.

If there are any queries, please do not hesitate to contact the writer at 09-2797192

Eileen Smith
Board Chair
Alzheimers Counties Manukau

C A R E T O R E M E M B E R

Making life better for all people affected by dementia Kia piki te ora mo ngā tāngata mate pōrewarewa

Appendix V

Letter from chairperson of Alzheimers NZ

Level 3, Adelphi Finance House
 15 Courtenay Place
 PO Box 3643
 Wellington
 Phone: 04 381 2362
 Fax: 04 381 2365
 E-mail: nationaloffice@alzheimers.org.nz
 Website: www.alzheimers.org.nz



affected by dementia
Kia piki te ora mo ngā
tāngata mate pōrewarewa
 Patron: Lady Hillary

11 July 2007

Grace O'Sullivan
 Doctoral Candidate
 School of Occupational Therapy
 Auckland University of Technology

Dear Grace

I am writing in response to your request to Alzheimers New Zealand to provide a letter of endorsement re your research.

At the time of request I was unclear as to whether Alzheimers New Zealand had a policy on endorsement of research and sought opinion from the Board re this. As there is no current policy, it was the view of the Board that the matter be put on the Agenda of the Board Meeting to be held on 28 June 2007 for further discussion. The email received from you clarified the point that you were seeking endorsement of research per se rather than your piece of research and/or yourself.

The matter was raised at the Board meeting and an interesting discussion followed. The results were:

- Point 3.3 of the Objects of the Alzheimers New Zealand Constitution clearly reads as follows:
3.3 stimulate and promote research in dementia, including treatment and care of people with dementia and disseminate findings.
- There is a need for Alzheimers New Zealand to put in place clear policy to ensure that this Object is met.
- The Board Legal Port Folio Holder is to pursue this matter and develop a draft Policy for the Board's consideration.

Thank you for raising this issue with Alzheimers New Zealand. It is important that such matters are raised and responded to.

We wish you well in your continued research.

Yours sincerely

Joy Simpson
 Board Chairperson
 Alzheimers New Zealand

Appendix W

A local level example of action cycle

Action cycle using Lewin's (1948) framework

A local level example

Observation: Recognizing that an application for funding to support the research journey might be more successful if it was endorsed by Alzheimer's NZ.

Reflection: Asked chairperson of a local branch of Alzheimer's NZ to sanction a funding application to the Families Commission Innovative Practice (June, 2007) funding round. The chairperson responded positively and suggested I write a letter to the general manager of that branch outlining the purpose of the study.

Act: Letter written and sent to the general manager seeking support for a funding application (16.6.07). The letter outlined the study to date and my efforts to actively challenge the attitudes that prevail in society towards people with dementia. In reply, the general manager of the local branch expressed doubts: *"I was unclear as to whether Alzheimers New Zealand had a policy on endorsement of research and sought opinion from the Board. As there is no current policy, it was the view of the Board that the matter be put on the agenda of the Board meeting to be held on 28 June, 2007."*

Reflection/Evaluation: This response caused me to wonder about the knowledge and understanding of those in authority at the local office. I was aware of disparity between the branches and for the first time I recognized a lack of cohesion within the organization.

Modify: The chairperson who was initially supportive of the plan was angered by this response and stated in an email: *"I am off to Wellington to the AGM, have had my nails painted red, to show I mean business!"* (27.6.07).

Act: Received a phone call from the local chairperson informing me of the outcome of the meeting. Evidently the request caused heated debate and the chairperson advised that some members of the board wanted to reject the application stating that: *"Alzheimers NZ does not support research of any kind."* However, another board member suggested that they should *"consult the charter."* It was found the charter clearly stated that the organization should: *"Stimulate and promote research in dementia, including treatment and care of people with dementia and disseminate the findings."* Consequently, board members decided that a new policy had to be developed before research could be endorsed. (See Chapter 6: Abuse of power).

Evaluate: Revelation of this internal strife increased my awareness of macro and micro power struggles as well as the need for external advocacy for people with dementia. This caused me to question the objectives, ambitions, awareness, values and understanding of staff within the national office, as well as the organization per se.

Action at a local level: Received a letter from the general manager of the local branch confirming the information previously received from the chairperson (16.7.07). The chairperson of the local branch of Alzheimer's sent a letter in support of a new funding application (16.9.07).

Evaluate: I was heartened to read the Executive Summary of Alzheimer's NZ Impact Report (June, 2008) under the heading 'Conclusions and Recommendations' that the first key point stated: *"Investment in research for cause, prevention and care in New Zealand setting."* What is more Alzheimers New Zealand has now established a Charitable Trust specifically for research activities. Titled: Small Projects Grants 2011, the purpose of the Trust is to provide a limited amount of funding for a small project or other research related activity focused on the medical or social aspects of dementia. These grants aim to support emerging researchers including (but not limited to) health professionals and academic researchers. This change in attitude from the national office provides clear evidence that my challenge precipitated change.

Appendix X

**Invitation to appear on the SUNDAY current affairs
programme at TVNZ**

From: Chris Cooke [Chris.Cooke@tvnz.co.nz]
Sent: Monday, July 05, 2010 3:40 PM
To: sullies@xtra.co.nz
Subject: SUNDAY - TVNZ

Dear Grace,

Recapping on my call; I am a producer with the SUNDAY current affairs programme at TVNZ.

With the rate of dementia set to double in the next twenty years I think our programme should be doing something on the issues for dementia care today and in the future.

I am interested in talking to you about your approach to caring for people with Alzheimers, particularly around the results you are getting in taking them off anti-psychotic drugs.

I would be very interested in talking with family members who have had first hand experience in seeing the benefits of this. Its is a very important topic so I hope they see this as a positive thing to be involved in.

Feel free to forward this email to anyone you think can help.

Talk to you tomorrow.

Kind regards

Chris Cooke
 SUNDAY
 TVNZ
 Ph 03 961 8542

=====

For more information on the Television New Zealand Group, visit us
 online at tvnz.co.nz

=====

CAUTION: This e-mail and any attachment(s) contain information that
 is intended to be read only by the named recipient(s). This information
 is not to be used or stored by any other person and/or organisation.

Appendix Y

An example of feedback from the SUNDAY programme

From: Sunday [Sunday.Sunday@tvnz.co.nz]
Sent: Tuesday, October 05, 2010 9:51 AM
To: Grace O'Sullivan
Subject: FW: Dementia Story

Hi Grace

FYI
 An example of the feedback we got...

Great ratings on the night

Talk when you get back

Best Max



Max Adams
 Field Producer - Sunday
 D. 64 9 916 7239
 F. 64 9 916 7778
 M. 64 21 461 326
max.adams@tvnz.co.nz

From: Kimberley Hammond [<mailto:Kimberley.Hammond@minedu.govt.nz>]
Sent: Monday, 4 October 2010 3:17 p.m.
To: Sunday
Subject: Dementia Story

Dear Sunday

7 years ago my father passed away from a pulmonary embolism that was likely the result of the cocktail of antipsychotic drugs he was prescribed. At the time he was 63 and was suffering from early onset alzheimers. He was considered to have some difficult behaviours (though not once did we observe these) and was consequently moved to a psychogeriatric home where he was given many drugs. Reading his medical records it is evident that he experienced many side effects as a result of these medications including hallucinations, shaking, drowsiness, incontinence and so on. But what is more concerning is that several drugs were given when they were counterindicated...a lethal combination in fact.

I cannot even express how pleased I was to listen to last nights story and hear that there are people like Grace O'Sullivan who are advocating for a non-medicated approach to care of people with dementia.

It is too late for my family, but if we had our dad here today St Andrews is just the place we would have liked him to have been a resident.

Well done Grace, and well done St Andrews.

Kindest regards,
 Kimberley

Appendix Z

An example of feedback from the SUNDAY programme (2)

From: Siobhan Molloy [siobhan@nzaot.com]
Sent: Monday, October 04, 2010 12:33 PM
To: Grace O'Sullivan
Subject: FW: Congratulations -Grace O'Sullivan

Hear hear - the programme was excellent - well done to you - a great ambassador for the profession.

From: otlam@googlegroups.com [mailto:otlam@googlegroups.com] On Behalf Of Christine King
Sent: Monday, 4 October 2010 12:31 p.m.
To: otlam@googlegroups.com
Subject: Congratulations -Grace O'Sullivan

Wow - what fantastic publicity for Occupational Therapy on the "Sunday" programme on TV 1 last night.

Hope everyone saw it & if not get on TVNZ on demand to see Grace O'Sullivan presenting on the role of Occupation for those with dementia (with the goal of reducing the use of anti-psychotic medication)

Siobhan can you pass this email onto Grace. What a fantastic ambassador she is for Occupational Therapy and how well the item articulated what we do and the value of Occupation...

I'll be making sure all my staff watch this item...and learn

Awesome stuff!!

Chris

This email has been scrubbed for your protection by SMX. For more information visit smxemail.com

Appendix AA

Evidence of international acclaim

From: Clare Hocking [clare.hocking@aut.ac.nz]
Sent: Wednesday, October 06, 2010 7:52 AM
To: sullies@xtra.co.nz
Subject: Re: Dementia Care

Hi Grace
 see below
 Clare

>>> Alison Wicks <alison@wicksmail.com> 5/10/10 11:13 p.m. >>>
 Thanks Clare, and congrats to Grace. I will link it to the Dementia Study and Training Centre here at UOW and also to the AOSC website.

Also, will Grace's keynote at the NZOT conference be published - if so, where?

Alison

On 5 October 2010 13:54, Kit Sinclair <sinclairkit@gmail.com> wrote:
 Thanks Clare,
 Got the link from Facebook last night and watched it through. Very good coverage and good on Grace. Saw your good self -briefly- giving Grace the award for OT of the Year.
 I will also pass the word.
 all best
 Kit

On Mon, Oct 4, 2010 at 11:41 AM, Clare Hocking <clare.hocking@aut.ac.nz> wrote:
 Hi Sharon, Marilyn, Kit, Ann, Beryl, Liz, Christine, Nils Erik, Alison, Wendy and Wendy
 thought you might be interested in this link, where Grace O'Sullivan, an occupational therapist and AUT PhD student made the benefits of occupation for people with advanced dementia abundantly clear
 Beryl, I understand the College of Occupational Therapists sponsored Grace to speak at the upcoming conference on dementia care at Stirling University. You might like to put the link on your website someplace
 Clare

>>> "Kirk Reed" <kirk.reed@aut.ac.nz> 5/10/10 8:09 a.m. >>>
 For those that missed Sunday which featured Grace O'Sullivan you can go to this link to view
<http://tvnz.co.nz/sunday-news/new-hope-dementia-sufferers-and-their-families-16-12-video-3815993>

Kit Sinclair, PhD
 WFOT Ambassador
 World Federation of Occupational Therapists
www.WFOT.org
 13 Wong Chuk Shan San Tsuen
 Po Lo Che, Sai Kung
 Hong Kong
 852-97326609

Appendix AB

Evidence of the North & South magazine award

NORTH & SOUTH

December 10, 2010

Dear Grace,

Congratulations from the *North & South* team on your being named winner of the Health & Medicine category in our 2010 New Zealander of the Year awards.

Your efforts – creativity, ingenuity, generosity, courage, persistence – help make New Zealand a better place for all of us. And we commend you.

Yours sincerely,

Virginia Larson

Editor, *North & South*

ACP MEDIA

Appendix AC

Evidence of Frances Rutherford Lecture Award

Frances Rutherford Lecture Award 2010

Presented to

Grace O'Sullivan

In recognition of an outstanding contribution to occupational
therapy in New Zealand.



President

A handwritten signature in dark ink, appearing to read 'E. Howland', is written over a horizontal line. The signature is fluid and cursive.

Date September 2010

Appendix AD

Abstract for University of Stirling Conference (London, 2010)

College of Occupational Therapists
University of Stirling
Coming of Age - Excel, London
21 October, 2010

AN OCCUPATIONAL APPROACH TO CHANGE IN DEMENTIA CARE

The title of this presentation – An occupational approach to change in dementia care is intended to convey a vision. Visions “begin in the minds eye, they begin with imagination and the belief that what’s merely an image can one day be made real.”

My vision for people who live with dementia in the community and in residential care is that they will live with a sense of satisfaction, regardless of cognitive decline. The essence of the vision is that the value of an occupational approach to supporting people with dementia will be recognised and encouraged to enable them to maintain skills and abilities and thus achieve the best possible level of functioning. This vision is grounded in the belief that optimum functioning is achieved by having something to do and, what is more, that *"life is given meaning by what we do."*

Over time, scientific evidence of the relationship between occupation and health has accumulated. The loss of opportunities to engage in daily occupations is associated with delayed recovery from ill health or in the case of people with dementia, declining abilities. Occupational therapy has a long-standing focus on enabling people to overcome human performance deficits. At this pivotal time in a changing world with shifting political, social, economic and environmental issues occupational therapy has the potential to change the way dementia is perceived. Educating society about the connection between health, occupation, and participation will give people who live with cognitive decline hope for the future. Everyone needs to have faith in the future. When faith is lost, hope is lost, because without hope people have nothing to strive for.

Appendix AE

Feedback from a person with dementia

From: agnes houston [agneshouston@hotmail.com]
Sent: Saturday, January 22, 2011 9:24 PM
To: Grace O'Sullivan
Subject: RE: DSDC Conference

Grace

Thank you so much for sending me you talk It was wonderful to be reminded of what you said what I remember was the feeling of she knows what she's talking about Thats what i want and need in my care and the word hope kept in my head and heart

So much so that the next time I was asked to speak I used it as an Accronym and said When you come to visit me please keep this work close to your heart and broke down

H - is for good health diet exercise and laughter and then went on to outline how this good be done

O - occupation what are my interest how can I keep doing what I like to do and how can you help me do this

P - Plan and prepare us for our future living with a diagnosis of Dementia

E - empower and enable us to embrace the challenges of living with dementia emptionally support us but let us do it for ourselves with a gentle touch approach But above all e is for enjoyment

Grace I want everyone to know of your work and what you are doing but alas I forget sometimes and things get mixed up so much so I am not writing my own material as much as I used to as and have to rely a lot on what I had done in my early days with Dementia

Please keep being our champion as we need more and more people thinking like you do

I'd like to keep in touch but if I forget you have a special place in my emotional memories in my heart.

Hugs and Rainbows
Agnes

Appendix AF

Evidence of international recognition of workplace

**The
International Dementia
Excellence Awards 2010**



Dementia Services
Development Centre

Team of the Year

**Henry Campbell House
St Andrew's Village**

Shortlisted

June Andrews

Professor June Andrews,
Director, Dementia Services Development Centre

NHS

Kensington and Chelsea

Award sponsored by

