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‘SUSTAINING PLACE’- HOW INFORMAL CARERS OF PERSONS WITH DEMENTIA ADDRESS THE PROBLEM OF ‘LIVING ON THE FRINGES’

A thesis presented to the University of Dublin, Trinity College for the Degree of Doctor in Philosophy

September 2010

By

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DEDICATION

For those who care …

DECLARATION

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‘SUSTAINING PLACE’ –

HOW INFORMAL CARERS OF PERSONS WITH DEMENTIA ADDRESS THE PROBLEM OF ‘LIVING ON THE FRINGES’

SUMMARY

Background and Aim Informal carers continue to provide the vast majority of care to persons with dementia and given the demographic projections, this is likely to increase in the future. Health and social care professionals’ have a responsibility to work with informal carers to ensure that they are supported in their role and that their needs and concerns are satisfactorily addressed. This is particularly warranted when it is considered that multiple aspects of an informal carer’s life can be affected due to the progressive nature of dementia. While there is already a considerable volume of research on informal dementia care, much of this has focused on: the content, impacts and consequences of the role, ways of coping and the nature of informal care across the trajectory of dementia. However, to date the social experiences and processes involved in this role have not been comprehensively accounted for. It is imperative that this gap in understanding is closed, if the actual concerns and support needs of informal carers of persons with dementia are to be addressed. Therefore, the aim of this study was to develop a theory to explain the processes employed by informal carers of persons with dementia to resolve issues of primary concern to them.

Research question The research question guiding the study was ‘what is the nature of living with dementia from an informal carer perspective?’

Methodology The study was conducted using a Classic Grounded Theory (CGT) approach and a social constructionist orientation informed the conceptualisation of the resultant theory. The data were collected in the course of thirty in-depth interviews, conducted with thirty one participants in the Republic of Ireland. The theory of *‘Sustaining Place’* was constructed using the tools of the CGT methodology. These included: concurrent theoretical sampling and constant comparative analysis, memoing and theoretical sensitivity. Ethical approval to conduct the study was obtained from the Faculty of Health Sciences in Trinity College Dublin and the Alzheimer Society of Ireland acted in the capacity of gatekeeper for the majority of participants.

Results The problem of concern to informal carers in this study was identified as *‘Living on the fringes’*. This problem refers to a significant and frequently negative alteration to informal carers’ relationships with and place within their life-worlds, which is caused by: a) dementia-related stigma and b) living a different life. In this instance, ‘place’ refers to a person’s situatedness within and among other people, organisations and societal structures and is interpreted in relational encounters. Importantly, the experience of *‘Living on the fringes’* also creates equal concerns for informal carers regarding the place of the person with dementia.

The theory of *'Sustaining Pla*ce' represents the social pattern of activities informal carers engage in to address this problem and has four components: 1) *'Unsettled place',* 2) *'Threatened place'*, 3) *'Sustaining our place'* and 4) *'Sustained Place'*. This theory begins with *'Unsettled place'*, as informal carers develop a growing perception of difference in various aspects of their known life-worlds that results in the realisation that this is due to dementia. In *'Threatened place'*, interpretation of the disruption to their sense of place and that of the person with dementia culminates firstly, in informal carers' recognition of the need to take action and secondly, their subsequent transition to *'Sustaining our place'*. This component describes informal carers' actions (*'nurturative protecting' and 'inter-relational labouring'*) to sustain place. These actions are facilitated by five enabling factors, which are: *'knowing the person with dementia', 'perceiving caring as a moral way of being', 'developing expertise', 'having a frame of reference' and 'strategising'*. *'Sustained place'* is the final component of the theory and is reached if the problem of *'Living on the fringes'* is addressed and a sense of place is restored. Interestingly, while *'Sustaining Place'* is described in terms of its four individual components, the theory is not linear. While *'Unsettled place'* cannot be re-visited, the other three components can. The theory's structure is consequently inter-connecting because there is a potential for an informal carer to transition between *'Threatened place'* and *'Sustaining our place'*. If an informal carer does reach *'Sustained place',* the potential to transition back to *'Threatened place'* also exists. As such, the theory is dynamic and can occur in relation to sequences of *'Sustaining Place'*. The theory therefore represents the diverse and individual nature of an informal carer's experience of living with dementia.

In conclusion This study conceptualises the problem of *'Living on the fringes'* and the theory of *'Sustaining* Place' which addresses it. The theory illuminates the experience of informal dementia care in the context of the social domains in which it occurs. *'Sustaining Place'* also demonstrates the ways in which understandings arising from various dementia discourses, impact on the informal carer's experience of living with dementia. Importantly, while *'Sustaining Place'* is of theoretical significance, it equally has a number of pragmatic implications. For example, the theory can be employed as a framework to facilitate the planning and implementation of specific policy and service level interventions to address the problem of *'Living on the fringes'*. The theoretical structure can also be used to tailor supportive interventions to meet an individual informal carer's needs, based on the carer's position in relation to the four components of *'Sustaining Place'*. Additionally, this theory can be utilised as a mechanism to direct and facilitate education and research. This is because *'Sustaining Place'* enables enhanced understanding of the complexity of informal dementia care by broadening the discursive construction of the phenomenon.

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To those who entrusted me with their experiences, this study and the understanding it generates is yours. Thank you.

TABLE OF CONTENTS

List of Tables

List of Figures

Chapter 1 Introduction

1.1 Introduction

This thesis presents the classic grounded theory (CGT) of 'Sustaining Place', which relates to the substantive area of informal dementia care. Informal carers are recognised as the "primary instrument" of continuing care for persons with dementia in society and an increasing focus of concern for health and social care policy and practice (Montgomery and Kosloski, 2009: 47). From the perspective of the informal carer, living with dementia can be a difficult challenge. As dementia advances, the informal caring role generally becomes more involved due to the progressive nature of dementia. While caregiver pathways are receiving increasing attention from the scientific community (Carpentier et al, 2008), the focus of this thesis relates more specifically to the processes informal carers of persons with dementia engage in along this route. The ways in which informal carers manage their situations in response to dementia care-giving experiences are not well understood, so research that attends to "parameters ... meaningful to carers" is required (Nolan, Grant and Keady, 1996: 26). If not, Barnes and Brannelly (2008) argue that inattention to the situations of informal carers may result in unmet needs and a compromised capacity to care. Health and social care professionals have a responsibility to support those who assume informal caring roles. To meet this responsibility, knowledge is required to enable professional care planners and providers to understand what it means to be an informal carer, the challenges and social processes involved and how carer identified concerns can be addressed.

1.2 Study context

The differences that result from the intrusion of dementia into the lives of those most closely touched by it, in this study informal carers, are multiple and varied. The actions of those who are primary informal carers for persons with dementia consequently involve multiple domains, for example: familial, social and occupational. Dementia is understood medically, as a disease with more than 200 subtypes (Clare, 2002; Hellstrom, Nolan and Lundh, 2005; Stephan and Brayne, 2008). More specifically, Stephan and Brayne (2008: 9) define dementia as "a group of syndromes characterized by progressive decline in cognition of sufficient severity to interfere with social and/or occupational functioning, caused by disease, trauma, and often associated with increasing age". The historical dominance of this medical understanding of dementia focused attention on the neuro-pathological changes in the brains of persons with dementia. This resulted in less consideration being given to care-giving relationships and contexts in dementia (Bond, 2001). However, the 1980's witnessed the emergence of an alternative perspective in which dementia was understood as an umbrella term for a disability resulting from multiple factors: neurological, social and psychological (Goldsmith, 1986; Kitwood, 1990, 1993a; Marshall and Tibbs, 2006). By emphasising the humanity of the person with dementia, this way of understanding led to the emergence of a revised culture of dementia care, which was a catalyst for a change in how persons with dementia were perceived (Kitwood, 1997). This resulted in the recognition of the need to uphold the personhood of persons with dementia (Kitwood and Benson, 1995; Kitwood, 1997). More recently, there have been calls for dementia to be understood in terms of networks of relationships and this has resulted in professional developments such as relationship-centred care (Nolan et al, 2002; Ryan et al, 2008) and calls for whole systems approaches to the field of dementia (Adams, 2008). Despite such advancements, the presence of dementia can still produce a negative perception of difference and possible stigmatisation and discrimination by others (Joachim and Acorn, 2000). This can result in actions that cause depersonalisation, disempowerment, exclusion and marginalisation of persons with dementia (Kitwood, 1997; Barnes, 2006). The resultant stigma can affect identity (Ablon, 2002). It also "deprives people of their dignity and interferes with their full participation in society" (The United States Department of Health and Human Services, 1999: 6). Dementia-related stigma is also a concern in relation to care provision, the well-being of persons with dementia and their quality of life (Sartorius, 1998; Reidpath et al, 2005).

Of central concern to this study, it is contended herein that there is an equal need to consider informal carers with regard to these issues. This is because the impact of socio-cultural influences on ways of understanding dementia, family caring structures and the provision of health and social care services, shape people's experiences of and responses to dementia (Downs, 2000). Health and social care interventions for informal carers of persons with dementia should recognise such experiences and be designed to improve the reported concerns of these persons. Interventions and support mechanisms should not simply be prescribed for with reference to professional concerns, as informal carers' actual needs may remain hidden and/or neglected. Recognising this, CGT was chosen as the research methodology in this study because the approach enables the conceptual explanation of what is happening in a substantive area, such as informal dementia care, from the perspective of those experiencing it. The theory conceptualised then relates to the "living reality" (Sabat, 2001: 16) of dementia, in this case from the perspective of informal carers. CGT consequently facilitates enhanced understanding and in doing so has the potential to inform policy, service design and practice interventions to enhance the quality of life of informal carers and potentially persons with dementia. To this end, the theory of 'Sustaining Place' (Chapters 6-9) that was conceptualised in this study explains how informal carers act to sustain their and the person with dementia's places-in-the-world when encountering the problem of 'Living on the fringes'.

1.3 The problem of 'Living on the fringes'

The problem of 'Living on the fringes' emerged from the data collected in the course of this study and is presented in this section so as to foreground the presentation of this thesis for the reader. The problem of 'Living on the fringes' refers to a significant and frequently negative alteration of the informal carer's relationship with and place within his/her life-world. Importantly, the experience of 'Living on the fringes' creates equal concerns for informal carers regarding the place of the person with dementia. 'Place'[1], as it is conceptualised here, concerns a person's situatedness within and among other people, organisational and societal structures and spaces. A sense of place is experienced and interpreted in the context of relational encounters, and alterations thereof, across the various aspects of the life-worlds within which informal carers and persons with dementia are situated. In this study, the term life-world refers to "the taken-for-granted mundane experiences of daily life as carried out in particular spatio-temporal settings" (Dyck, 1995: 307). The data illustrate that having a valued place is important to informal carers because it is recognised by them and those they interact with. The concept of place is closely linked with one's social identity and ultimately affects how a person is regarded by others. In the presence of dementia, 'place' assumes particular importance for informal carers because after assuming the caring role, taken for granted and unquestioned ways of living become significantly changed, as illustrated here:

"I found it, that the interests that I had, I just had to drop them." [CFM02][2]

"[I] mean I can't go to any army functions that I used to go to ..." [CFM03]

"... I had to be very careful, I mean we [participant and her husband] used to go for a drink socially, right, and we had to stop doing that..." [CFM07]

This leads to a perception of 'Living on the fringes' of what was, what was anticipated, and what could have been. Informal carers can experience a binary existence, being in and yet not in

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[1] The concept of 'place', as it is conceptualised in this thesis, will be explored in depth in Chapter 10, Section 10.2.

[2] The abbreviation CFM is used here to indicate participant quotations from informal carers and AHPDO2 refers to an Allied Health Professional and Disability Organisation participant who had also been an informal carer for a person with dementia.

their life-worlds, as a consequence of fractured social connectivity. For example, one daughter carer explained this as follows:

"I was angry at that too [the impact of dementia on different aspects of this participant's life] because I, this was a time in my life when it should have been me and my family. I was rearing kids for so many years and all that and working hard to get where we were and all that." [CFM15]

The data in this study suggest that the problem of 'Living on the fringes' is stimulated in two ways, one or both of which can be present:

1. Dementia-related stigma (its components and consequences).[3] Due to the presence of dementia, the informal carer and the person with progressive dementia can be perceived as different, devalued and experience an altered estimation of social standing, as shown in the following exemplars:

"That's the way stigma is to me and because they're broken [persons with dementia] and just leave them 'cos they're old and I think that's what it is with a lot of them [other people]." [CFM12]

"But I know people are still talking about stigma I know that. And a lot of my friends [other informal carers] in the Alzheimer's support group meeting would tell me that." [CFM15]

Participants' accounts of the stigma-related experiences encountered by informal carers are supported by professional concepts, such as courtesy stigma or stigma by association (Goffman, 1963; Blum, 1991; MacRae, 1999; Werner, Goldstein and Buchbinder, 2010). This phenomenon implies that informal carers can be subject to the same or similar reactions as those with a stigmatising attribute. In this study, informal carers perceive this can result in experiences where they and the person with dementia are regarded differently, and in some cases negatively by other people, organisations and society, and that this poses a threat to their sense of place. The following is an example of how this was illustrated by one participant:

"Mm... [other people] don't want to go down that road [dementia] ... ignorance, a lot of ignorance and ignorance gives us stigma, maybe it's in the family?... it's, that's what I'm trying to get, it's people's reactions [avoidance] ... they "don't want to know about it

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[3] The concept of 'stigma' will be discussed further in Chapter 10, Section 10.4.

[dementia]." [AHPDO2, who was both a formal and informal carer, referring to how people in society react to dementia]

2. Living a different life. In this study, informal carers report that they and the person with dementia are subject to a variety of non-stigma related experiences that contribute to the problem of 'Living on the fringes'. For example: a loss of connection to their previous relational interactants and contexts, dealing with unknown structures and systems, progressive change in the connection amongst themselves and for informal carers, feeling trapped due to the increasing constancy of involvement that informal caring can entail. Living a different life was portrayed by informal carers in some of the following ways:

"Very, very, trying circumstances because you're loosing the person you loved [participant's husband who had dementia], you can see them going ..." [CFM02]

"My role as a mum, I would say my role as a wife. I mean he [participant's husband] was so good ... only for him being so good I would never have gotten through it [caring for her mother with dementia]. But my role with him we could not plan, which we used to do, go off for a drive, up the mountains. I said I couldn't do that anymore. And I said to him, you go or go with the girls [participant's daughters] or whatever, go with the lads. And then I would feel very mad about that." [CFM15]

" [Participant interrupts researcher – vehemently] I don't go anywhere!" [CFM16]

"Oh you [informal carer] doesn't come into it I don't think. That is the big problem that you just don't seem to think about yourself at all. Even to get out for a walk." [CFM17]

As shown above, both dementia-related stigma and living a different life were conceptualised from the data as underpinning the problem of 'Living on the fringes' in this study. Having identified this problem, as the main concern of informal carers, the theory of 'Sustaining Place' (Chapters 6 – 9) was conceptualised from the data to explain the latent social patterns that carers engage in to address this problem. 'Living on the fringes' is therefore the problem that the theory of 'Sustaining Place' addresses.

1.4 Overview of this thesis

This study relates to the substantive area of informal dementia care. While the thesis is presented in discrete chapters, which can be read in a stand-alone fashion, each chapter when read consecutively builds to an appreciation of the context, conceptualisation, substance, significance and implications of the theory of 'Sustaining Place'.

Chapters two and three begin by exploring the ways in which dementia (Chapter 2) and informal dementia care (Chapter 3) are constructed as discursive objects. These chapters elucidate the context from which the theory emerged and within which it is situated. The reader is exposed to the social constructionist lens, which emerged as salient in the conceptualisation of the theory and the parameters of current understanding. The purpose of these opening chapters is to foreground the presentation of the theory of 'Sustaining Place' and to present an overview of some of the literature that informed my theoretical sensitivity. These chapters were formulated as the conceptualisation of the theory was well advanced and the relevance of their content became evident. This is consistent with the use of literature in CGT and ensures that the conceptualisation process was not driven or forced by a particular conceptual framework.

Chapters four and five explain the approach to and the manner in which the theory of 'Sustaining Place' was conceptualised. Chapter four discusses the epistemological, ontological and methodological positions that guided the development of the theory. In this chapter, the stances taken in relation to the philosophical positioning of the CGT research approach and the various grounded theory debates will be clarified. In so doing, the appropriateness of CGT to this study will be justified. Chapter five explains my research praxis; the ways in which I applied the methods of CGT and how I engaged with the iterative processes involved in the construction of the theory.

The remaining chapters present and then discuss the theory of 'Sustaining Place'. Chapters' six to nine elucidate each component of the theory, how they inter-relate and how an informal carer may transition between them. In chapter ten, the theory is discussed in relation to where it sits in terms of current thinking and how it may advance extant positions. In the final chapter, situational and quality considerations are addressed and the implications and recommendations arising from the conduct of the study and the theory of 'Sustaining Place' will be presented.

1.5 On a personal note

While this thesis can be dated to its official beginning in 2006, to truly appreciate its evolution and my place within the process, it is necessary to return to my time in clinical practice. I am a general nurse who primarily practiced clinically in an acute general hospital. The majority of my practice in this setting was within the context of a unit caring for older persons. In practice, one of the most challenging and yet most enjoyable components of my role was working with persons with dementia and their informal carers. While striving to work with and provide a quality of care which met these persons' needs, I admit that I struggled to understand the realities of dementia and their implications for the interpretation of the lived life and people's actions. This need to understand, as a foundation on which to provide meaningful care that enhances quality of life, has continued throughout my career and was further amplified when a close family member experienced cognitive impairment. It was at this time that I personally came to appreciate that thinking I knew and knowing were two very different entities. In my subsequent roles, as a nurse tutor, education facilitator with the Dementia Services Information and Development Centre in the Republic of Ireland and lecturer, I have tried to increase my understanding as a basis on which to do better. For example, in my Masters degree, I engaged in research to increase understanding of nurses' experiences of dementia care practice in an acute general hospital setting. However, I have increasingly recognised that to make a positive difference to the experiences of persons with dementia and those who support them, a different understanding is required that can best be uncovered using approaches that enable those living with dementia to voice their perspectives. It was this joint background of my personal experience and professional practice that ignited my passion for the study presented in this thesis.

The construction of the theory of 'Sustaining Place' had its formal genesis in a study exploring stigma in relation to dementia (which was funded for an initial six months by the Alzheimer Society of Ireland, with part funding from the National Disability Authority) (Nolan et al, 2006).[4] The study continued and following a thorough engagement with the components of CGT, including further analysis of the data and the collection of additional data, the theory of 'Sustaining Place' was conceptualised. In the process of completing this thesis, I faced a number of challenges:

- learning 'the how' of classic grounded theory – which was truly an on the job learning experience,

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[4] The Louise Nolan referred to in this reference is Louise Daly the author of this thesis.

- managing professional concerns (for example the concept of 'stigma'), while learning to discern and focus on the concerns of participants,
- managing my professional dementia care knowledge and experience,
- balancing well-being (participants and mine), the demands of CGT and those of my higher institute of learning and
- 'not knowing' - overcoming the at times paralysing effects of uncertainty that being a PhD student and grounded theory neophyte entail.

In the end, my mastery of these challenges boiled down to two dictums reiterated by Dr B Glaser: the first to 'trust in emergence', by using the CGT methodology and the second to just do it. What follows is the outcome of my trusting in emergence and my record of how I did it. It is suggested that excellence in dementia care must begin with an understanding of what it means to live with dementia (Phinney, 2008).[5] The theory conceptualised in this study aims to bring the reader a step closer to this aim by advancing understanding of the phenomenon of informal care for persons with dementia. By providing enhanced understanding of the experiences and actions of informal carers, 'Sustaining Place' has the potential to positively impact on policy, services and practices designed to improve the lives of those who live with and care for persons with dementia. It is hoped that the theory fits, works and is relevant to this end.

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[5] In this study, the term 'live with dementia', is understood to refer to the perspective of informal carers, unless otherwise stated.

Chapter 2 Constructing dementia

> "Disease is at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine's intellectual and institutional history, an occasion of … potential legitimation for public policy, an aspect of social role and individual – intra-psychic – identity, a sanction for cultural values, and a structuring element in doctor and patient interactions. In some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it" (Rosenberg, 1992: Xii).

2.1 Introduction

This chapter will explore the main discourses that inform current understandings of dementia. Chapter 3 will then consider how informal dementia care is constructed by examining the empirical research relating to informal carers of persons with dementia. It is important to foreground the presentation and discussion of the theory of 'Sustaining Place' (Chapters 6-9), which relates to the substantive area of informal dementia care, by exploring the ways in which these phenomena are constructed through discourse. This is because informal carers' experiences and actions are affected by encounters with people, organisations and society, which in turn are influenced by understandings communicated through these discourses. In this chapter, dementia will be shown to be a phenomenon that is constructed in various ways, which are reinforced in the context of social interactions in everyday, familial, institutional, policy and social settings. As these constructions impact on the ways people understand and act in the presence of dementia, they contribute to the creation of the problem of 'Living on the fringes' (Chapter 1, Section 1.3) and the subsequent need for informal carers to engage in 'Sustaining Place'.

2.1 Constructing the literature review

The literature review elucidates the extant "parameters of the conversation" one hopes to enter and where one's theory makes a contribution (Lempert, 2007: 254).[6] While a review of the CGT

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[6] The literature consulted in the course of this research was sourced using various methods. Computerised searches were conducted of databases such as the Cumulative Index of Nursing and Allied Health Literature, EMBASE.com, IngentaConnect, Science Direct, Medline, Pubmed and Psychlit and the archive databases of specific journals, for example Aging and Mental Health. Both free text and thesaurus searches were carried out using key words and combinations thereof that emerged at various points in the research. The holdings of the Library at Trinity College Dublin and key policy documents and dementia

literature and a limited review of that relating to stigma were conducted in the first six months of this study,[7] an in-depth review of the informal care and dementia literature was delayed. This is consistent with Glaser's (1998) advice to engage in wider reading of literature to sensitise oneself to the array of possibilities and to delay reading of literature related to the substantive research area. According to Heath and Cowley (2004), learning not to know is a requirement if one is to remain sensitive to one's data in a grounded theory study. Delaying literature consultation enables conceptualisation of patterns emerging in research data through as fresh eyes as possible (Alvesson and Skoldberg, 2000). This is despite a risk of having too weak an insight and potentially reproducing what is already known (Lempert, 2007). Such a risk was minimised in this study because of my knowledge and experience of dementia, which in turn was derived from my background in nursing. While not unduly influencing the conceptualisation process, these provided an important frame of reference (Chapter 5, Section 5.10.7). Generally in CGT, relevant literature becomes identifiable as the theory begins to emerge and can be viewed as more data to contribute to the analysis. At that point, I began a focused and extensive consultation of the literature. This chapter, the one that follows and the discussion in Chapter 10 consequently foreground and contextualise the theory of 'Sustaining Place'.

2.3 Discourses and dementia

Discourses are "powerful structures of ideas, values and representations", which organise people's illness experiences (Scott, 2009: 118). Specific discourses are time, culture and context dependent and they provide a range of shared meanings and symbolic resources, which individuals or groups draw from. According to Butler (2002: 45), discourses classify and illuminate a subject matter and have a "power-enforcing function" enacted by those within a social grouping. It is within the nexus of discourses that social reality (in this study the social reality of informal dementia care in particular) is constructed and reproduced and people grasp how they understand the world and their place within it (Westerhof and Tulle, 2007). Cassell (1976) suggests that different ways of understanding dementia impact on the experience of living with dementia and health and social care approaches to supporting those whose lives are touched by dementia, including informal carers. This is because discourses influence

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related websites were consulted. In addition, reference lists of sourced materials were also searched to increase capture of relevant literature. Where possible, sources were original and published in refereed professional journals. The literature sourced was all in English and represented a varied geographic spread. A paucity of related Irish research literature was found, supporting the need for the study.

[7] The review was conducted to meet the requirements of the initial funder. The literature review was published as part of the following report, Perceptions of Stigma in Dementia: an Exploratory Study (Nolan et al, 2006).

obligations, responsibility and authority for different subjectivities (including: informal carers, persons with dementia, formal carers, service planners, policy makers and so on) (Chambers and Narayansamy, 2008). Discourses are consequently frames or schemas that enable interpretation of the pertinent structure of experience in a particular moment of social lives (Goffman, 1974). They also function as social truths that work in the interests of certain groups. Discourses are produced and maintained through social relations that sustain certain types of knowledge and permit or prohibit certain behaviours. In this way, they "map out the space in which social practices are made possible" (Westerhof and Tulle, 2007: 236). Therefore, the complexities of dementia, including the experience of informal dementia care, can in part be related to the following discourses that constitute its common meanings:

1.3.1 Dementia – a demographic cataclysm,
1.3.2 Normalising dementia – an age related process,
1.3.3 Medicalising dementia – a pathological process,
1.3.4 Laicising dementia – a feared process and
1.3.5 Socialising dementia – an inter-relational experience.

2.3.1 Dementia – a demographic cataclysm

This discourse is concerned with the social construction of dementia as a burgeoning demographic fact. It is frequently drawn on by the media, policy makers and those seeking to secure resources to raise awareness, support service provision and dementia research. Demographic estimates relating to dementia are frequently presented in conjunction with those regarding the rising ageing population and the implications for society and resources (Johnson and Clarke, 2003; National Council on Ageing and Older People, 2004; Johnson, 2005; Hodson and Keady, 2008; Timonen, 2008).[8] Thus, demographically dementia is primarily constructed as an occurrence of later life and via quantification dementia is constructed as a 'real' problem. For example, according to the Alzheimer Society of Ireland, there are currently approximately 44,000 people with a diagnosis of dementia in Ireland (Alzheimer Society of Ireland, 2009a). However, this is probably an underestimation because many persons may be living with dementia, but without formal diagnosis (Department of Health, 2009). This number is predicted to increase to 104,000 by 2037, an increase of 303% from 2002, while the population grows by less than 40% (O'Callaghan, 2008). These statistics are cause for concern when one considers that the majority of persons with dementia are over 65 years and that this age group is also the fastest growing in the population. The projected increases are consistent with global predictions for a doubling of dementia every twenty years, from the current estimate of 24.3 million to 81.1

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[8] For a critical exploration of population ageing conceptualised as a burden or a challenge, see Timonen (2008).

million by 2040 (Ferri et al, 2005). Writers, such as Berchtold and Cotman (1998), consequently refer to Alzheimer's disease as a problem of near catastrophic levels. Others refer to calamitous estimations of the accompanying economic and resource burdens to society (Robertson, 1991; Berr, Wancata and Ritchie, 2005; Pastios and Davey, 2005; O'Shea, 2007; Brown and Chen, 2008). Dementia is consequently constructed as a "worldwide epidemic" (Stephan and Brayne, 2008: 26) and a "disease of the century" with insufficient resources available to meet exponentially rising demands (Ballenger, 2008: 503). Robertson (1991: 144) terms this an "apocalyptic demography", representing "the social construction of catastrophe".

Concomitant with the effects of societal burden, resulting from the financial and resource impacts, is the acknowledgement that dementia is personally burdensome to informal carers (Gaines and Whitehouse, 2006; O'Shea, 2007; Kim and Schulz, 2008).[9] This compounds the construction of dementia as an important public health issue and dementia care being conceptualised in terms of the "social problem and political arithmetic approach to the study of ageing" (Victor, 2005: 299). It is though concerning that informal care is situated outside of the market economy. As a result, informal dementia care can be socially and politically hidden and its fiscal value is not widely recognised (Arno, Levine and Memmott, 1999). However, this discourse can be viewed as beneficial to informal care, in that it is used to enable the identification of dementia as a focus for policy, research and development investment (Harding and Palfrey, 1997; Cheston and Bender, 2003; Naue and Kroll, 2009). In consequence, many countries now have national dementia and informal care policies/strategies (O'Shea and O'Reilly, 1999; Department of Health, 2008, 2009). In addition, the work of advocacy organisations is frequently underpinned by specific dementia manifestos such as that of the Alzheimer Society of Ireland (2006). Drawing on this discourse has consequently enabled the prioritisation of dementia, resulting in significant progress in terms of understanding and treatments, with the promise of significant future progress (Berchtold and Cotman, 1998). Therefore, the demographic discourse is important because the allocation of resources is dependent on dementia's "characterisation and its geography of affliction" (Gaines and Whitehouse, 2006: 65). There is a need for the naming and quantifying of 'dementia' in order to allocate resources to support persons with dementia and, of particular concern in this study, to support informal carers.

However, this discourse is simultaneously limiting in that it could result in a blame culture directed at older people who are seen as responsible for demographic related social problems (Estes and Binney, 1989). As constructing dementia in terms of demography suggests that it is

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[9] See Chapter 3, Section 3.5.3

reaching epidemic levels, the cost of policies designed to address this concern could contribute to financial alarm (Gubrium, 1986; Hughes, Louw and Sabat, 2006a).[10] Brooker (2007) concurs suggesting that prejudice arises where resources are scarce. This is further compounded when dementia demography is aligned with ageing demography (Section 2.3.2), increasing perceptions of dependency and resource and expenditure requirements (Henwood, 1992). Another critique of this discourse is that it can contribute to a hidden demographic in dementia - that of younger persons aged less than 65 years with Younger Onset Dementia, estimated to be 4,000 people in Ireland (Alzheimer Society of Ireland, 2009a). Haase (2005) concludes that this has resulted in a lack of resource allocation to meet the needs of this demographic sub-group.

In relation to informal carers, the demographic discourse frequently constructs those who care as instrumental resources. This has contributed to the emergence of community care policies (Government of Ireland, 2001) and Home Care Support Packages (Department of Health and Children, 2008). These are designed to pre-empt a need for admission to acute or continuing care services. However, it is suggested by some that this is a double edged sword. For example, Nolan, Grant and Keady (1996) highlight that while specific policies are clearly assistive, the emphasis on instrumental aspects of caring can do informal carers a great disservice. They suggest this is because the less quantifiable, more humanistic components of care do not appear to be as valued. Additionally, services and supports to assist informal carers of and persons with dementia are often geographically and budget dependent. They are also are subject to questions, regarding who they are designed to benefit (Nolan, Grant and Keady, 1996): the person with dementia, informal carers, health and social care systems and/or society?

2.3.2. Normalising dementia - an age-related process

This discourse constructs dementia as an age-related process and is drawn on in historical accounts of dementia, in literature, by the public, some health professionals and/or researchers. The association between older age and cognitive decline was noted by the Greco-Romans as early as pre-modern times (notably by Plato, Aristotle, Pythagoras and Galen) and later by writers including Shakespeare (Berchtold and Cotman, 1998). While the term 'dementia' was not always employed, there was cognisance that advancing age could be accompanied by, and for some was inseparable from, cognitive decline (Boller and Forbes, 1998; Karenberg and Forstl, 2006). Early in the 20th century, those who developed dementia in later life were thought

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[10] An example of the impact of decisions relating to the cost of dementia can be seen in the recent controversy surrounding NICE Clinical Guideline No 42 (National Collaborating Centre for Mental Health, 2007) and its denial of acetlycholinesterase inhibitor drugs to those in mild stages of dementia and the potential impact on carers.

to do so because of natural ageing and the term senile dementia was used to describe this phenomenon (Downs, 2000; Ballenger, 2006). According to Gubrium (1986), attempts to differentiate between normal and abnormal were intended to create order from the disorder resulting from dementia. However, the boundaries that separate normal ageing from dementia are considered by some to be less distinct than ever today, despite advances in fields including genetics and neuro-imaging (Gaines and Whitehouse, 2006; Kirkwood, 2006). For example, using this discourse in one way suggests that both the pathological, clinical and behavioural changes associated with dementia can be commensurate with normal ageing (Gubrium, 1986; Downs, 2000; Downs, Clare and Mackenzie, 2006). Berrios (1994: 19) refers to this position as the 'continuity view'. In contrast, some writers note that cognitive decline is normative with advancing age, but differentiate between cognitive decline and cognitive impairment (Corner and Bond, 2004). Others infer a difference of degree and not essence, some suggesting a threshold effect (Lishman, 1994) or others a cognitive continuum model (Ferris and Kluger, 1996). This suggests that cognitive decline can be understood as a range of decline across a spectrum from optimal ageing to severe dementia (Ferris and Kluger, 1996; Hodson and Keady, 2008).

Similarities observed at the pathophysiological level, between those with and without dementia, have also contributed to the construction of dementia as normative in later life. For example, Huppert and Brayne (1994) identify dementia as primarily age dependent and that many of the associated pathological and cognitive-behavioural changes are synonymous with those seen in 'normal' ageing. These writers suggest this could be interpreted in two ways: 1) unique dementia related changes are yet to be identified or 2) dementia and normal ageing are a continuum "differing in degree but not in kind" (Hupert and Brayne, 1994: 3). According to this second option, increasing age-related diversity complicates the differentiation between normality and abnormality. This is supported by seminal research, such as the Nun's study (Snowdon, 2001), which demonstrates some of the same neuropathological changes in those labelled as having dementia and those not having dementia. Similar findings have also led to assertions that brain changes deemed typical of Alzheimer's type dementia are normative in older people (Sabat, 2001; Corner and Bond, 2004). It is consequently suggested that Alzheimer's disease is less a disease than a cultural construction related to the interpretation of normality and biologic variation in ageing (Doka, 2004; Gaines and Whitehouse, 2006). So while ageing is positively constructed by some, it is just as frequently equated with illness and decline. In consequence, some societies consider later life as synonymous with pathology and abnormality (Estes and Binney, 1989). Within this discourse, dementia is then understood as an accompaniment of later life, which is simultaneously normal and pathological (Holstein, 1997).

If dementia changes are constructed in terms of normal ageing, one benefit is the implication that the pre-change status afforded to a person can be maintained (Downs, Clare and Mackenzie, 2006). This is supported by Jones, Chow and Gatz (2006) and Sahin et al (2006) who found that some Chinese Americans perceived dementia-like changes to be normal and this in turn affected how they acted in relation to dementia. Accordingly, this discourse could be used to positively support the maintenance of continuity between those who live with dementia (informal carers and persons with dementia) and society. However, limitations are also evident. Where dementia is constructed as normal (or as not abnormal) in later life, there may be a perception of a less explicit need to allocate additional resources. This discourse could also lead to delayed presentation and help-seeking, with informal carers attempting to meet care needs without support. Research has further suggested that some health professionals may delay referral of the older person with dementia to specialist services because of therapeutic nihilism in terms of the available possibilities to positively intervene (Cahill et al, 2006). Corner and Bond (2004) found that such reactions were related to both a lack of value for older people and reduced expectations. Finally, in contrast to the demography discourse, which tends to subjugate the needs of younger persons with dementia, up to the mid 20th century, those presenting with dementia earlier in life were understood to have a pathology (Holstein, 1997). Thus, dementia was constructed as either: pre-senile and abnormal (stimulating a search for effective interventions and cure), or senile and related to advancing age (in which case the impetus for intervention was not as great). As such, the attribution of cognitive impairment as not unexpected in advanced age has historically slowed progress and understanding of dementia (Berchtold and Cotman, 1998). The impacts of this are still felt in terms of the prioritisation of dementia and indeed lay and some professionals' understanding of dementia and dementia care. However, when the demographic discourse is drawn upon, this effect is somewhat counterbalanced because the need to prioritise dementia is numerically clear.

2.3.3 Medicalising dementia – an abnormal process

This discourse is concerned with understanding dementia in terms of certain neuro-pathological changes in the brains of persons with dementia and the naming of dementia as a disease. The construction of dementia as a medical problem is one of the most dominant dementia discourses and has been referred to as the standard paradigm (Kitwood, 1997; Cheston and Bender, 2003). This discourse has assumed such eminence that Hill (2001) suggests at times it has almost drowned other constructions of dementia. It is primarily drawn on, to greater or lesser degrees, by health professionals, researchers, policy makers and those who live with dementia, including informal carers and persons with dementia. Medical discourse constructs the body as a value free biological entity (Armstrong, 1983). It emphasises individual organic pathology, aetiology and biomedical intervention (Estes and Binney, 1989; Ray, Bernard and Philips, 2009). Within this discourse, dementia is most commonly constructed as a number of progressive, irreversible biomedical entities that are characterised by particular hallmarks, for example: β-amyloid plaques, neurofibrillary tangles and a reduction of acetylcholine in Alzheimer's disease (Davis, 2004; Gaines and Whitehouse, 2006). This discourse infers that pathological brain changes are responsible for the clinical manifestations of dementia in the affected individual and that ongoing changes are equated with advancing progression of the diseased brain. Understanding dementia in this way contributes to the construction of dementia in terms of losses. Those diagnosed with dementia are then frequently perceived as "victims of an incurable disease that [will] inevitably rob them of their personalities, identities, insight and abilities" (Ray, Bernard and Philips, 2009: 55).

Medical states relating to dementia have existed since classical times. Early Romans referred to dementia as insanity or being out of one's mind (Berrios, 1994). The Latin stem 'dements' became prevalent in the 17th and 18th centuries, at which time dementia was a general term with a number of meanings (Berrios, 2004). An understanding of cognitive failure, as the essence of dementia, emerged in the late 19th century. The science of neuropathology then enabled the construction of a "discontinuity view", suggesting that ageing (though associated) was not synonymous with dementia (Berrios, 1994: 19). The medical construction that emerged thus enabled dementia to be viewed as a concrete entity to be investigated and managed, if not eradicated (Robertson, 1991; Harding and Palfrey, 1997). At that time, persons with dementia existed beyond mainstream society in asylums and institutions and became what Adams (2008: 21) refers to as the "forgotten people". The person receded and the objective body (or a component thereof) became the focus of attention (Koch and Webb, 1996).

Early in the 20th century, as somatic evidence for mental illness began to emerge, dementia became a recognised term for a number of disorders (Berrios, 1994; Huppert and Brayne, 1994; Berrios, 2004).[11] This construction was supported by physicians and researchers working primarily within psychiatry, such as Krapelin who in 1912 applied the term 'Alzheimer's Disease' to those who developed dementia before age 65.[12] The mid century then witnessed a neglect of dementia, with nosological interest arising again in the latter half of the century (Harding and Palfrey, 1997; Martinez Lage, 2006). Pre-senile and senile dementias became

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[11] The construction of dementia as a mental illness can be traced through the literature documenting the history of dementia. The following sources provide a more extensive overview of the history of 'dementia': Berchtold and Cotman (1998), Berrios (1994), Holstein, (1997), Boller and Forbes (1998), Berrios (2005), Karenberg and Forstl (2006), and Gaines and Whitehouse (2006).

[12] Interestingly, Dr Alzheimer (who worked with Krapelin) supported a continuity perspective of ageing and dementia (Berrios, 1994; Whitehouse and George, 2008).

recognised as synonymous and a great deal of dementia-related scientific activity ensued (Lishman, 1994; Pearlin et al, 2001; Ballenger, 2006). The medical diagnosis of dementia today is primarily clinical and one of exclusion, when other potential causes for what is observed are out-ruled (Cheston and Bender, 2003). A medical diagnosis of dementia is usually made when a person fulfils set criteria. For example, those constructed for Alzheimer's disease including: the National Institute of Neurological and Communicative Disease and Stroke/Alzheimer's Disease and Related Disorder Associations (NINCDS/ADRDA) (McKhann et al, 1984) and the Diagnostic and Statistical Manual IV criteria (American Psychiatric Association, 1994).[13]

While presented as providing objective and valid understanding of phenomena, science, and in this case medicine, generally promote the existence of truths without consideration of the inter-relation of social and historical contexts (Vincent, 2008). However, using his genealogical approach, Foucault (1979) suggests that medical discourse came to prominence due to increasing control and surveillance of the body and behaviour and not because of some form of evolutionary progression. Thus, Foucault (2002) identifies contemporary medicine as a social practice. Due to the resultant medicalisation of social issues, people can be viewed in terms of dependence (Philips, 2007). Medicine can then regulate individuals through governmentality and technologies of the self designed to affect people's conduct (Faubian, 2002). As such, scientific medicine constructs illness as pathology located within the body of the individual (Lupton, 2003). Using this discourse, the powerful influence of medicine's clinical gaze (Foucault, 1973) then constructs dementia in terms of decremental change and a legitimate concern of biomedicine (Estes and Binney, 1989). The medicalisation of dementia thus reinforces medicine's authority over those with dementia (Robertson, 1991; Harding and Palfrey, 1997). Solutions to dementia-related problems are then sought in the person (Bond et al, 2002; Cheston and Bender, 2003). The effects of dementia on the informal carer (Chapter 3, Section 3.5.2 and 3.5.3) are perceived similarly. However in this instance, informal carer personality factors are highlighted and not the material and structural conditions that affect people's experiences and actions (Bond et al, 2002).

The benefits of the construction of dementia as a medical disease include the allocation of resources for research to enhance biomedical understanding and to produce effective therapeutic interventions (Harding and Palfrey, 1997). Informal carers also draw on biomedical knowledge to structure their understanding of the pathology and manifestations of dementia. This knowledge explains what informal carers observe happening to their loved one. In consequence, the disease and not the person can then be held responsible. Biomedical discourse also enables

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[13] NICE-SCIE Clinical Practice Guideline Number 42 (National Collaborating Centre for Mental Health, 2007) provides an overview of the various recommended diagnostic criteria for other forms of dementia.

access to systems and organisations that provide assessment and the assignation of a diagnostic label. This then facilitates entitlement to specific treatments, supports and services. The discourse also creates the possibility of disease amelioration and potential cure. This is reinforced through research and the emergence of new interventions and pharmaceutical therapies. Therefore, medicalisation of dementia can provide comfort and may create a sense of hope (Gaines and Whitehouse, 2006); if not for a particular individual, then for the future. Finally, in the midst of the disorder that accompanies dementia, medical discourse provides some control (Bond, 1992; Gaines and Whitehouse, 2006). Control here refers to the use of stages and a temporal disease trajectory. This can enable the imposition of order and a level of predictability that can provide informal carers with some psychological relief and reassurance of stage matched formal care responses (Harding and Palfrey, 1997; Martorell Poveda, 2003).

However, Bond (1992) identifies a number of negative implications of the medicalisation of dementia. These include: expert control, social control through the assignation of social status, individualisation of behaviour (the problem is in the person not society) and de-politicisation of behaviours. It is also suggested that understanding of dementia has been impeded by an over-reliance on this discourse (Downs, 2000; Cheston and Bender, 2003). According to Hill (2001), in-depth examination of medical texts demonstrates contradiction in relation to how particular aspects of dementia are understood, for example cause. Importantly, the medical lens is suggested to "offer a nearsighted view" by failing to account for the impact of social forces affecting the "definition, production and progression of dementia" (Lyman, 1989: 600, 604). Constructing dementia solely as an organic disease is perceived as a fallacy beacuse it lacks consideration of the social and psychological influences, de-emphasising a humanistic perspective of the person with dementia and informal carer (Gubrium, 1987; Kitwood, 1997; Snowdon, 2001; Whitehouse and George, 2008). Gillet (2004: 735) supports this, suggesting medical discourse cloaks subjectivity, holism and the interactivity of the person "whose being-with and belonging-to relationships replete with issues of power and resistance, are vital to their health".

The medical understanding of dementia also suggests that disease progression is usually accompanied by a loss of competency. Marson (2001: 268) defines competency as "an individual's legal capacity to make certain decisions and to perform certain acts". A diagnosis of dementia can therefore result in an assumption that persons with dementia lack the capacity to make decisions on their own behalf. According to Bartlett and O'Connor (2007: 109), holding a view of persons with dementia as deficient in insight and lacking the ability to express their needs, effectively silences them. This is both inhumane and an infringement of personhood. It is also problematic because a diagnosis of dementia does not imply an absolute lack of capacity to consent to treatment, research or other activities (Marson, 2001). Because of this, it is recommended that in the presence of dementia, capacity related decisions are made on an individual basis (Bartlett and Martin, 2002). Therefore, the medical and legal discourses surrounding dementia demonstrate points of digression even though they are related. However, beliefs arising out of both discourses, about the impact of dementia on competence and capacity, may negatively articulate with the lay discourse of dementia (Section 2.3.4). This may occur because the association with capacity loss may exacerbate public fear connected to dementia. In consequence, while the classical medical science approach to dementia does have an important role, it is reductionist. This is because it pays insufficient attention to the reality of persons experiencing dementia (Harding and Palfrey, 1997). It also pays insufficient attention to the experiences of informal carers. Instead, medical discourse focuses on mechanical and molecular concepts and emphasises research in which elements of cognitive functioning are isolated, whereas in living these elements are not experienced separately (Sabat, 2001; Whitehouse and George, 2008).

This discourse can also be a double edged sword for informal carers. According to Hill (2001), it would appear that medicine has had only limited success in fostering co-operative care with other carers. As Ballenger (2008) notes, it marginalises care and particularly support for care-giving in a trade off with support for a focus on and research into dementia the disease. The medical focus is on the person with dementia and not the informal carer, their position or lived experience (Adams, 1998). If this is the sole perspective informing the practice of health professions, it can marginalise those relied on to provide the majority of care. In addition, the construction of dementia as a neuro-psychiatric condition has situated dementia primarily within the psychiatric discipline of medicine. This is the case particularly when behaviours that challenge are evident. However, the stigma related to psychiatric services has resulted in a questioning of the location of dementia care within this context. The person with dementia can be subject to stigmatising, dehumanising and disenfranchising effects similar to other people with mental health difficulties (Graham et al, 2003; Downs, Clare and Mackenzie, 2006). This is because adopting a defectological view of the person with dementia (Sabat, 2001; Beard, Knauss and Moyer, 2009) can create a conception of difference leading to negative treatment by others. By association this difference may extend to informal carers (Blum, 1991; MacRae, 1999; Angermeyer, Schulze and Dietrich, 2003; Chang and Horrocks, 2006). As such, portrayals of dementia that are influenced by medicalising discourse have contributed to the lay construction of dementia in terms of fear (Jolley and Benbow, 2000).

2.3.4 Laicising dementia – a feared process

This discourse constructs dementia in terms of being a feared entity. It is commonly drawn on and reproduced by the public and historically the media (although this is increasingly less frequent). According to Brooker (2007: 29), "dementia is the most feared aspect of ageing" and representations from popular understanding have resulted in a negative picture of dementia and those labelled as having it. This discourse is commonly associated with loss of function, control and a sense of connection to others (Robertson, 1991). The potential for such losses is considered significant in a society in which capacity and autonomy are considered important values. Therefore, the social construction of dementia in terms of such losses can instil a fear, which has the potential to exacerbate the negative effects of illness (Bond, 1992; MacRae, 2008). Whitehouse and George (2008: 43) also indicate that the way in which dementia is constructed, creates "fear, angst and social stigmatisation" for those diagnosed and those ageing in society. Research supports the existence of dementia-related stigma among the lay public. For example, Kitwood (1997) suggested that people can react negatively to those with dementia, due to an inherent and subconscious fear of mortality and loss of mental stability. Thus, similar to the demographic and normalising discourses, this discourse again links ageing with dementia creating a perception of later life as a "terrifying and monstrous experience" (Martorell Poveda, 2003: 29).

Research continues to support the existence of this fear of dementia. Gershenson, Hodgson and Cutlier (1997) explored the relationship between anticipatory dementia (fear that normal age related memory loss is indicative of dementia) and wellbeing. They found that those reporting higher levels of anticipatory dementia were found to have lower levels of well-being. More recently, Werner, Goldstein and Buchbinder (2010) have elucidated what they term Alzheimer's related 'lay public stigma' in a study reporting the subjective experiences of children of persons with Alzheimer's disease. Corner and Bond (2004) also reported that their participants felt uncomfortable in the presence of friends and family with dementia and were reluctant to report memory problems to doctors. Additionally, as with Werner, Goldstein, and Buchbinder's (2010) findings, the presence of dementia was linked to a perception of family stigma. Clearly, negative stereotypes relating to older age and dementia can significantly affect people both before and after receiving a diagnosis (Scholl and Sabat, 2008). While the association of dementia with psychiatry in medical discourse may be assistive in terms of policy making and facilitation of service access (Section 2.3.3), this association is clearly problematic in terms of lay discourse.

People with mental ill health are frequently conceived of as socially deviant, sometimes violent and stigmatised (Mora-Rios et al, 2008). A significant implication of this is that the associated social taboos could negatively influence help-seeking and early presentation (Morgan et al, 2002; Corner and Bond, 2004). Doka (2004) also suggests that in western society, dementia is culturally constructed through language, as indicative of insanity and the potential for dangerous behaviour. This is problematic in what Post (2000a) refers to as a hyper-cognitive western society that values intact high functioning mental status and self-determination, but can lead to a discounting and potential stigmatisation of those who cannot fit this model. This includes persons with dementia and by association informal carers. The context within which the current study was conducted was considered to reflect this perspective. While increasingly multi-cultural, in terms of the numbers of older persons and the experience of dementia, Ireland to date remains relatively culturally homogeneous, though this could change in the future. However, it is acknowledged that some other cultures and subcultures may view dementia and dementia care-giving differently (Doka, 2004). For example, Post (2000b) highlights that in China, and Sahin et al (2006) in Turkey, dementia is not as feared because it is perceived as natural (see Section 2.3.2 also). O'Connor, Phinney and Hulko (2009) consequently suggest that research, which considers the influence of culture, can challenge certain constructions of dementia. Clearly, it is necessary to identify the forces that influence its negative meanings so as to understand the dread associated with dementia (Davis, 2004).

According to Susan Sontag (1991: 6), "any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious". She suggests that in modernity, illness metaphors are indicative of a schism between the person and society. "Disease equals death" and people labelled as having a disease can be belittled (Sontag, 1991: 81). Those illnesses that are most feared are those that are not just lethal but dehumanising. Whitehouse and George (2008) indicate that dementia, and specifically Alzheimer's disease, are now deeply a part of our culture and the related metaphors are embedded in everyday language. Words, labels and attitudes can affect self and societal perceptions of dementia (Braudy Harris and Keady, 2008). These can then impact on persons with dementia, their families, carers and members of society. Indeed, there have been calls for the abolition of the use of the word dementia, partly as it is not a definitive diagnosis and also because of the negative associations that accompany the word. However, as I have shown, and as Braudy Harris and Keady (2008) suggest, 'dementia' is embedded within both medical and lay public discourses and cannot be easily removed from either common language or people's memories.

The portrayal of negative imagery in various media (for example, literature, print media, film and television) is also suggested to contribute to the creation of fear in relation to dementia.

Resultant discrimination against those with dementia can relate to misunderstanding because of stereotypical representations, which are then perceived as difficult if not impossible to dispel (Penn et al, 1999). A number of seminal reviews of the available research have found that mental illness has been frequently mis-represented. This is because the images portrayed have been mainly negative, depicting violence, dangerousness and un-likeability, although some improvement has been noted more recently (Wahl, 1992; Wahl, Wood and Richards, 2002). This is important because Adams (1999) suggests that the public's awareness of dementia impacts on those who live with dementia. Thus, Stout, Villegas and Jennings (2004) highlight the role of the media as a socialising agent, although they acknowledge that more research is needed, particularly to explore current media images of mental illness and their associated impacts. Of particular concern in this thesis, is that Martorell Poveda (2003) considers that the public cultural conception of Alzheimer's disease also negatively represents the impact and meaning of dementia for families. They are to be understood as the hidden victims and caring is then pathologised (Zarit, Orr and Zarit, 1985; Martorell Poveda, 2003). For example, Roberston (1991) refers to carers as the real victims, while Doka (2004: 42) suggests the carer-spouse can be viewed as becoming a "crypto widow" who is married in name only.

According to Gubrium (1986) and MacRae (2008), fear of dementia does have some benefit in that it is has led to the recognition of dementia as a serious public health issue. This has strengthened the impetus for research and resource allocation. While public fear of dementia remains evident, there are indications of change (Clare, 2002). The potential of the popular media to better portray dementia, reduce stigma and expose people to more positive images of mental illness is increasingly recognised (Adams and Clarke, 1999; Byrne, 2000, 2001). For example, Graham et al (2003) offer specific suggestions as to how the media might reduce stigma.[14] In addition, media campaigns, such as those run by the Alzheimer Society of Ireland and their guidance to the media in using dementia appropriate language and how to interview persons with dementia (Alzheimer Society of Ireland, 2009b), may facilitate education, understanding and better portrayal of what it means to live with dementia. Finally, the fear associated with dementia is opposed and potentially ameliorated when dementia is constructed and understood in terms of an inter-relational experience.

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[14] They identify the following examples: avoidance of disseminating stigmatising and discriminatory material, awareness of the possibility to create myths, recognition of a responsibility to be informed, reporting of appropriate information and raising the need for and awareness of services, supports and associations.

2.3.5 Socialising dementia – an inter-relational experience

This discourse is concerned with the construction of dementia in terms of an inter-relational process. The social perspective is one of the most recent discourses to gain recognition and has given rise to the social disability and citizenship perspectives on dementia (Chapter 10, Section 10.5). As previously demonstrated (2.3.3), the medicalisation of dementia suggests that it is the functional limitations caused by impairments that are responsible for the experience of dementia. However, it is otherwise suggested that chronic illness and/or disability is best conceptualised as an interface between the biological and psycho-social worlds (Rolland, 1994). This is because individuals do not solely create their states of health or illness (Hardin, 2001). For example, Downs (2000) acknowledges the heterogeneity of persons with dementia and the need to consider social and contextual factors as pivotal influences on the experience of and response to dementia. A social frame also suggests that dementia is compounded by human factors (Tregaskis, 2004). This is because society is not structured in ways that impairments are accounted for. According to C. Wright Mills (1963), private troubles are really public issues. While disease is commonly constructed to be located and problematised within the person, to understand personal troubles we actually need to look to the wider milieus in which values are perceived to be threatened (Wright Mills, 1963). Therefore to better understand dementia, a wider lens is required to explore the ways in which the contexts in which lives are lived affect the experience of dementia. Within this discourse, disease is therefore not solely embodied. Rather, the nexus for disease is within the social spaces among people, the "interstices of relationships, in the social body" (Armstrong, 1983: 8). Embodied individuals are consequently positioned not in static social spaces, but in terms of ranked relations that are analysed through ongoing surveillance (Foucault, 1973; Armstrong, 1983).

According to Degnen (2007), declines in mental acuity and social comportment are subject to particularly critical monitoring and complete personhood is accorded to those who fulfil socially sanctioned criteria of physical, social and cognitive performance.[15] Clearly beliefs relating to social groupings' attributes, affect perceptions of and behaviours towards others. By implication, it is possible that beliefs relating to persons with dementia can exert a relational affect and persons with dementia are at risk of not being seen as full equals. In relation to informal carers, the attribution of a dementia label is also a concern in relation to how carers are perceived and positioned. While there are advantages, such as access to medical and social resources, negative psychosocial implications can occur. For example, Carpentier et al (2008) refer to the dementia-related social representations that carers create, which reflect a number of

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[15] Kitwood (1997: 8) defines personhood as "a standing or status … bestowed upon one human being by others, in the context of relationship and social being".

factors, including: family complexity, beliefs, and fear of stigmatisation. These writers suggest that representations are formulated in a contradictory context, in which an informal carer is subject to a plethora of messages, values, beliefs and subtle social pressures that can impede or guide their actions.

While it might then be suggested that this discourse offers little potential to positively affect action to improve the lives of those who live with dementia, including informal carers, this is not the case. There are a number of important epistemological and social benefits to the construction of dementia as an inter-relational process. Firstly, this discourse emerged to locate the voice of the person with dementia (Goldsmith, 1986). The seminal writings of Kitwood (1990, 1997), and subsequent work inspired by him, have resulted in the identification and implementation of positive psychosocial supports for persons with dementia and informal carers.[16] Kitwood (1996) conceptualised dementia in terms of the following equation: D [Dementia] = P [Personality] + B [Biography] + H [Health] + NI [Neurological impairment] +SP [Social psychology]. This construction broadened understanding of dementia by emphasising the importance of the inter-relationship of a range of factors that contribute to dementia-related difficulties including: individual reactions to neuropathology, how others behave in the presence of dementia and how persons with dementia [and their informal carers] react to how they are treated by others (Sabat, 2001). Kitwood's (1997) work suggested that drawing on this discourse, these factors can be ameliorated by promoting personhood through positive person work (for example: recognition and facilitation of agency). Such work would be designed to oppose the depersonalisation that accompanies dementia-related malignant social psychology, examples of which include: outpacing, withholding, treachery, infantilisation, labelling, invalidation, disempowerment and objectification (Brooker, 2007). This is because when interpersonal discourse is privileged, the self can be sustained as a valued person (Kitwood, 1997; Davis, 2004). As such, Hill (2001: 73) highlights that Kitwood (1990) was concerned with the bio-psycho-social processes involved in producing dementia in contrast to medicine's focus on "diagnosing and defining the state of dementia". This in turn led to the emergence of person-centred models of dementia emphasising the *Person* with dementia in contrast to the person with *Dementia* (Brooker, 2007; Christie and Cunningham, 2009).[17]

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[16] This work was preceded by the psychodynamic perspective of dementia that emerged alongside social gerontology in the 1930's recognising that psychosocial factors contributed to the aetiology of dementia, perceived as a dialectical process between the brain and the psychosocial context (Ballenger, 2006).

[17] Person-centred care is defined by Brooker (2007) as: PCC (person-centred care) = V (valuing people with dementia and those who care for them) + I (treating people as individuals) + P (looking at the world from the perspective of the person with dementia) + S (a positive social environment in which the person can experience wellbeing).

Another benefit of this discourse is that constructing dementia in inter-relational terms can potentially counter the less desirable affects of some of the other discourses, in which those with dementia and informal carers may be viewed as deviant and/or problematic. The inter-relational construction of dementia enables understanding of how negative interactions with people, organisations and society can infringe personhood. It does so by explaining that the way in which informal carers and persons with dementia are treated accounts for many of the so called dementia-associated losses (Sabat and Harre, 1992; Downs, Clare and Mackenzie, 2006). In consequence, this discourse also explains the excess disability that can accompany dementia (Brody et al, 1971; Sabat, 2001). This is important as loss of self is a frequently cited concern in relation to persons with dementia (Kitwood and Bredin, 1992; Kitwood and Benson, 1995). However, using this discourse research demonstrates that absolute loss of self should not be assumed. For example, Beard, Knauss and Moyer (2009) found that persons with dementia do not experience such a loss and that they incorporate dementia disability into their identities. Other writers and researchers identify that dementia associated 'losses' can be expedited or limited according to how those with dementia are treated (Sabat and Harre, 1992; Kontos and Naglie, 2007; Baldwin, 2008a). To counter this, the understanding facilitated by this discourse offers the potential to construct positive interactions designed to sustain personhood. This is because, according to Degnen (2007: 71), "the self is forged in multiple social registers and multiple contexts ... through experience and action in the social world". Therefore, social contexts can modify the relevancy of beliefs (Kruse and Schmitt, 2006).

Similar to other discourses, dementia constructed as an inter-relational process is subject to critique. In the first instance, the construction of dementia solely in these terms is not possible and would limit understanding. The discourse is also sometimes critiqued as individualistic when emphasis is placed on the promotion of personhood in the person with dementia (Adams, 1998), in contrast to the reciprocal nature of inter-relationships (Nolan et al, 2002). This could imply that informal carers are not positioned centre-stage with the person with dementia, with resultant implications for their wellbeing, policy, provision of services and supports. However, the position and personhood of informal carers and other relevant stakeholders also needs to be prioritised. A number of contemporary developments are evident in this regard. For example, research emphasising relationship-centred care (inclusive of informal carers, the person with dementia and professionals) (Nolan et al, 2002; Forbat, 2008; Ryan et al, 2008) and whole systems approaches (Adams, 2008) are two examples of epistemological advancement to this end. The emergence of the social disability model of dementia also emphasised the influence of socio-political phenomena on the construction of dementia (Adams, 2000, 2008). Marhsall and Tibbs (2006) thus construct dementia in terms of an impairment that becomes a disability because of the social and built environment. This model highlights the way in which persons with dementia and those who care for them can be marginalised and excluded as a result of the disability (Ray, Bernard and Philips, 2009).

The recent citizenship approach to dementia further emphasises the right to social inclusion and participation in taken for granted activities. This approach reminds us that citizenship travels in two directions and that those with dementia [and their informal carers] are experts with much to offer (Marshall and Tibbs, 2006). Sabat (2001) suggests that in light of the progressive nature of dementia, there is a need to explore the social and psychological issues encountered by those with dementia. This is equally necessary for informal carers who can experience profound change in their relationships with the person with dementia and important others (Davis, 2004). This discourse emphasises intentional social action by constructing informal carers as social interactants. Informal carer concerns can then be located within the relational context of caring and not simply in terms of the affects and manifestations of neuro-pathology on the person with dementia. Adams (1998, 2008) concurs, highlighting the need for a means of understanding that emphasises the inter-relationship between all those involved in the construction of dementia. Similarly Kontos and Nagle (2007), who draw on Davis (2004), advocate for a view of the person in terms of social interconnectedness. The social construction of dementia in terms of an inter-relational discourse facilitates this.

2.4 In summary

This chapter presented a critical perspective of the discourses, which structure commonly held understandings of dementia. It was demonstrated that dementia is commonly understood in terms of: a demographic cataclysm, an age related process, a medically sanctioned disease, a feared process and an inter-relational experience. These discourses were shown to be both organised and organising representational frames that, according to Wetherell (2001), act as resources enabling the interpretation of social phenomena. Dementia was also shown to be a phenomenon that is continuously in the making, arising from particular historical moments (Martorell Poveda, 2003; Gaines and Whitehouse, 2006). Understanding gained herein supports what Hill (2001) refers to as the need to de-privilege the standard medical discourse of dementia as superior to other constructions. This is necessary because different discourses are sanctioned and operate in particular contexts and people can and do draw from more than one discourse (Downs, Clare and Mackenzie, 2006). Operating solely from within a particular construction of dementia would limit one's view by inhibiting the benefits of envisioning from within multiple ways of knowing and experiencing dementia. This is because it is within the dynamic and co-existent perspectives that power and resistance occur and within which informal carers and persons with dementia are situated and occupy social positions and roles (Carpentier and

Ducharme, 2005; Naue and Kroll, 2009). Hughes, Louw and Sabat (2006b) consequently identify the need for whole sight, while Gillet (2004) argues for a more liberal attitude towards knowledge and its discovery.

Discursive knowledge is also necessary to understand and challenge taken for granted approaches to dementia and informal dementia care, which could limit a researcher's gaze and to enable alternative conceptualisations of the experiences and actions of informal carers. Holstein (1997) concurs suggesting that when certain forms of knowledge are placed over others, freedom to speculate is threatened if not lost. Instead, cognisance of the various constructions of dementia can encourage "epistemological experimentation" (Holstein, 1997: 2) and an understanding of how power and resistance are evidenced in dementia (Faubian, 2002). Having recourse to multiple dementia discourses also enables understanding of the possibilities of how knowledge of dementia is constructed and how holding a particular view grants and limits possibilities for different social actors, in the case of this study informal carers. This in turn can facilitate a more meaningful appreciation of the situation of informal carers. Similarly, O'Connor et al (2007: 130) highlight the significance of considering the importance of the socio-cultural context within which dementia is experienced, in order to avoid conveying an impression that such experience "occurs in a vacuum". The primary concern in this thesis is with the way in which different constructions of dementia are used and how they manifest and impact on the lives and actions of informal carers. For example, how dementia is constructed can impact on how dementia is interpreted and whether or not treatment is sought and/or offered and the meanings, actions and inter-actions encountered in the presence of dementia. It can also affect people's views of the person with dementia and informal carers, as either valued or as in some way compromised. Having explored the social construction of dementia and the implications for informal dementia care, the next chapter will examine the ways in which informal dementia care itself is also socially constructed and understood within research.

Chapter 3 Constructing Informal Dementia Care

3.1 Introduction

Chapter two explored the different ways in which 'dementia' is commonly constructed. The purpose of this chapter is to examine the ways in which 'informal dementia care' is constructed by addressing Gubrium's (1995: 267) question "What is this thing some call caregiving?". To this end, the emergence of 'informal care' will be explored briefly, as the term has a surprisingly recent provenance in the private, public and political domains. Following this, to elucidate the context in which this study was conducted, the Irish context of informal dementia care will be described. The majority of the chapter will focus on providing a critical interrogation of the phenomenon of informal dementia care as it is constructed in empirical literature, in order to foreground the presentation of the CGT of 'Sustaining Place' (Chapters 6-9).[18]

3.2 Informal care

It is suggested that caring is intrinsic to our lives and central to primary relationships, but that it is only when caring becomes unequal within relationships that we treat it as a particular role (Keogh and McGettrick, 2008). For those in need of care, including people living with dementia, there are generally two overarching sources of care support: formal care provided by statutory, private and voluntary services and informal care provided by unpaid family, friends and/or others. It is the dynamic interplay of these forms of care that constitute community care (Pastios and Davey, 2005). This said, the majority of community care has always been and continues to be provided with little public cost by informal carers (Hooyman and Kiyak, 2008). While there is no universally agreed definition of the phenomenon, there is general agreement that informal care is multidimensional, involving care provision outside of formal statutory or voluntary payment structures and generally in the cared for person's home (Fast, Williamson and Keating, 1999; Lane et al, 2000; Vitaliano, Zhang and Scanlan, 2003; Chappell and Parmenter, 2005; Victor, 2005; Adams, 2008). Colello (2007: 1) defines such caregiving as a wide variety of "activities, services and supports to assist persons who are limited in their capacity for self-care because of a physical, cognitive or mental disability or condition that results in a functional impairment and dependence on others". Keating et al (1997) further

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[18] Literature pertaining to caring and specifically to dementia care (informal, formal and policy perspectives) is vast. It would neither be helpful nor appropriate, to this study, to attempt to address this literature in its entirety. Therefore, this chapter is mainly limited to an exploration of the literature relating to informal dementia care and the wider informal care literature is included where particularly relevant.

suggest that informal care involves the relationship between the caregiver and receiver, while Brouwer et al (2005) conceptualise informal care as that provided in the social environment of the recipient. Hooyman and Kiyak (2008) identify four such care forms: emotional support, instrumental activities (in and outside the home), person care and contacting or monitoring service providers. Similarly, other writers indicate that informal care can encompass physical, emotional and informational supports and importantly that the nature of care relates to the individuality of the person needing care (Harlton, Fast and Keating, 1998; Vitaliano, Zhang and Scanlan, 2003; Rogero-Garcia, Prieto-Flores and Rosenberg, 2008; Wilkins, Bruce and Sirey, 2009).

Constructions of informal care, similar to dementia, are historically and socially situated (Dalley, 1996; Heaton, 1999). Garey, Hansen and MacDonald (2002) relate the interest in care related issues to practical considerations about care and kinship, but also to care as a public dilemma that society is faced with. Prior to the 1980's, informal carers were not greatly acknowledged in either the public or policy domains. Bowers (1987) and Jansson, Nordberg and Grafstrom (2001) refer to this as the invisibility of caring, which was facilitated by societal structures of the time. Heavily linked to kin relationships and obligation (Philips, 2007), informal care was to an extent constructed as an unquestioned component of women's family work (Walker, Pratt and Eddy, 1995; Adams, 2008; Bytheway and Johnson, 2008). Early research (1970's - 1980's) illustrated the significance of such care, contradicting a belief that older people were lonely, isolated and abandoned by relatives and social contacts (Chappell and Parmenter, 2005). However, it was in the next wave of research (1980's-1990's) that an explicit discourse of informal care emerged (Heaton, 1999). This was signified by a move from 'care in' to 'care by' the community (Walker, Pratt and Eddy, 1995; Victor, 2005). The transition witnessed a policy emphasis on enabling older people needing care to remain at home. This was designed to facilitate aging in place and continued connection to informal networks, which were perceived as best placed to respond to care recipients needs (Keating et al, 1997). Accompanying this shift, the explicit role of family and friends as care resources emerged in political and policy agendas, as did the 'care for the carer' approach (Adams, 1998; Heaton, 1999; Victor, 2005; Duffy, 2009). At a macro policy level, this approach was linked to fears that emphasising formal community and home services could compromise the willingness of informal carers to provide care (Pastios and Davey, 2005).[19] This was a concern because the cost of dementia care is enormous and with rising numbers of persons with dementia, it was

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[19] At the meso level, Twig and Atkin (1994) suggest that practitioners draw on a number of constructions of informal carers: as care resources, co-workers in terms of the planning and delivery of care, co-clients alongside the original care recipient or superseded, following the placement of the care recipient in a professional care environment.

suggested that sustaining informal care could offset the costs of formal care (Bosanquet, 2001; Colello, 2007). For example, one United States (US) study found that direct costs of dementia care were 20.8% lower for persons with dementia living at home, compared to those in residential settings (Zhu et al, 2006).

Ward-Griffin and Marshall (2003) acknowledge the resultant move away from formal care provision and a return to reliance on informal carers. Innes (2002) further highlights that welfare policy in the US for those with dementia is tolerated only in so far as it does not impinge on the public (and particularly the wealthier in society) who might then be taxed to pay for care. Thus, Levy (2006) suggests that the US provides less public support for caring than other countries, instead promoting care as a matter of individual responsibility. This suggests that while lauded in policy as "a virtue of our society" (Fortinsky, 2001: S35), informal care is clearly seen as a means to reduce spending on service provision (Adams, 2008). As such, related policy is devised to take advantage of the family unit (Dalley, 1996; Montgomery and Williams, 2001; Chappell and Parmenter, 2005). However in Ireland, as in other jurisdictions, changing family structure is characterised by a move away from larger extended traditional families to smaller families and a lessening proportion of married couples (Population Health Directorate, 2008). Changes in family configurations and the number of women in paid employment are consequently concerns in relation to carer availability and the costs of care (McDaid, 2001; National Council on Ageing and Older People, 2001; Pastios and Davey, 2005; Brooker, 2007; The Carers Association, 2008; Duffy, 2009). It is suggested though that these concerns may be moot, as decreasing carer numbers are reported to be refuted by empirical data (Victor, 2005). In light of this, the need for a balanced consideration of the increased costs to informal carers and more effective support mechanisms have been identified (Arno, Levine and Memmott, 1999; Zhu et al, 2006).

However at a micro level, informal care is a personal construct in which the lived nature of care is experienced and interpreted. Victor (2005) believes that such care is subject to obligations and rules affecting the giving and receiving of care within, between and across generations. Assumption of this role is generally gradual (Hooyman and Kiyak, 2008), though Given and Given (1991) suggest that the process is poorly understood. O'Connor and Ruddle (1988) identified a combination of factors that lead to becoming a carer: demographic factors (relationship to the person requiring care, family size, composition and marital status), antecedent events (changes to the health status of the older person) and situational factors (feeling responsible, proximity and availability). Motenko (1989) described similar positions out of which caring occurs, including: the need to reciprocate past attentions, the continuation of meaningful marital relationships and a sense of responsibility or duty. Dementia specific research also relates the role to: a moral duty (Wilson, 1989a, 1989b; Gates, 2000; Zabalegui et al, 2008), an expansion of caring about someone (Pearlin et al, 1990) and reciprocity in family roles (Willoughby and Keating, 1991; Fast, Williamson and Keating, 1999; Perry and O'Connor, 2002). These findings indicate that caring encompasses the inter-relations among people (Garey et al, 2002; Bytheway and Johnson, 2008). This includes the associated labour, feelings and a concern for and assumption of responsibility for another's well-being (Jansson, Nordberg and Grafstrom, 2001). Philips (2007: 5) thus positions care "as an interdependent and connected concept" that takes its place among the multiple functions that people perform.

Today, informal care is suggested to be a "typical experience" and its economic, social and psychological consequences are of distinct interest to a variety of stakeholders (Pearlin et al, 1990: 583). The reasons for this include: demographic changes, increased longevity, the associated rise in chronic illness and accompanying costs of care (Pearlin et al, 1990). In society, there are now fewer people in the home, declines in multi-generational household members, greater geographic distance among close kin and more women in paid employment (Garey et al, 2002; Chappell and Parmenter, 2005; Brooker, 2007; Hooyman and Kiyak, 2008). As indicated previously, this could imply that informal carers may not be as available and has resulted in informal care becoming more visible and a growing focus for policy-makers, representative organisations, researchers and practitioners. However, according to Chappell and Parmenter (2005: 168, 173), informal carers have always cared and "this remains true today ... despite trends ... that were supposed to test this commitment". Worryingly though, Keady et al (2007) consider that the situation of informal carers has remained largely unchanged over time. In Ireland, it is acknowledged that understanding of informal care is particularly limited, for example in relation to carers' perceived health and social care needs (Lane et al, 2000; McGee et al, 2008). However, as the population ages and the number of persons with dementia rises, the need to understand the phenomenon of informal care, including its facilitating and impeding factors, is increasingly essential (McGee et al, 2008).

3.3 Informal dementia care - the Irish context

As with the demographic discourse on dementia (Chapter 2, Section 2.3.1), informal dementia care can be constructed in terms of the numbers of those involved. However, in the absence of National Databases of persons with dementia and informal carers, it is difficult to identify precisely the number of informal carers of persons with dementia and to access and understand their experiences. O'Shea (2003, 2007) estimates there are approximately 50,000 Irish carers of persons with dementia, providing a median of 10-12 hours care per day and more than 80 hours of care per week. Similarly, in a European survey of carers of persons with advanced dementia, George et al (2008) found that half of the carers provided care for more than 10 hours per day and one third cared for 14 or more hours. Such statistics support the contention of Hooyman and Kiyak (2008) that the number of hours and length of care increase for informal dementia carers when compared with other carers. This is concerning as the duration of dementia is estimated to be in the region of 7-12 years and the care needs of this population are high and resource intensive (Department of Health, 2009). Most persons with dementia (84%) live with and/or are cared for by their families in the community (Alzheimer Europe, 2006; Algase, 2007). The continued inadequacy of formal supports and quality continuing care options mean that informal care at home is often the only option available to many family members (Pearlin et al, 1990; The Carers Association, 2008). Even if a person with dementia is admitted to a continuing care setting, informal care continues albeit in differing ways (Almberg et al, 2000; Chappell and Parmenter, 2005). As such, Goldsteen et al (2007: 2) refer to dementia as "a disease of the relatives".

As the number of persons with dementia increases, the socioeconomic value of informal care will continue to rise globally (Vitaliano, Zhang and Scanlan, 2003), particularly where cutbacks in state funding are a growing reality (Ward-Griffin and Marshall, 2003). The last two decades have witnessed Irish reforms that recognise the need for informal and supportive community care (National Council on Ageing and Older People, 2001; Department of Health and Children, 2006; Health Services Executive, 2006; Department of Health and Children, 2008; Health Services Executive, 2008). However, only 6% of the cost of Irish dementia care (€400 million in 2006) is attributable to community care (O'Shea, 2007). In addition, this cost is frequently calculated in terms of public expenditure (Fast, Williamson and Keating, 1999), which contrasts markedly with the actual costs (personal, financial and other) to informal carers and savings made through care provided free by them (Georges et al, 2008). O'Callaghan (2008) consequently estimates that Irish informal carers provide 57% of the value of dementia care without compensation. In the United Kingdom this figure is 60% (Bosanquet, 2001). This suggests that the situation of informal carers is referred to with much rhetoric. Informal carers consequently provide high levels of care with low levels of support and restricted choice, particularly where a diagnosis of dementia is lacking (Arksey and Glendinning, 2007; Department of Health, 2009).

3.4 Informal dementia care - who are the carers?

Informal dementia care has traditionally arisen through kinship links of family and marital associations that connect people in networks of care relationships (Keady et al, 2007; Adams, 2008).[20] It frequently involves the family unit where one or two people assume a primary caring role and are supported by other family members (Knight et al, 2007; Adams, 2008). Conceptualised in this way, an informal carer may be any family member from within the same (spouse or sibling) or a different generation (children or parents) (Victor, 2005). A hierarchy is however suggested to exist in relation to expectations of who will take on the caring role (Philips, 2007): spouse, daughter, daughter-in-law, son, other kin and non-kin (Huckle, 1994). Research suggests that spousal carers tend to be the oldest carers and this is likely to increase (Duffy, 2009). Jansson, Nordberg and Grafstrom (2001) and Mittleman (2003) also report that the majority of family caregivers are spouses and frequently women. Thus, older men are more likely to be cared for by their spouses (Given and Given, 1991; Chappell and Parmenter, 2005). However, older women are more likely to be cared for by adult children and mostly daughters (Mittleman, 2003). Colello (2007) relates this to women having a longer life expectancy and because traditional views of caring being a woman's role are still held by many. Recent research questions such findings. For example, a United Kingdom study found that for older (non-dementia specific) carers there was no gender difference where carers were co-resident (Mesenthos and Triantafillou, 2005). Svenhuijsen (2003) also identifies the relocation of care in general from women to men, in that men are providing increasing levels of informal care as women play greater public roles, for example within the paid labour force.

In the United States, it is now suggested that men account for 41% of spousal carers (Witucki Brown et al, 2007). Therefore, the equal role of older men as carers is increasingly recognised and there is a growing body of research exploring how gender affects the nature, meaning, context and outcomes of caring (Perry, 2002; Raschick and Ingersoll-Dayton, 2004; Pinquart and Sorenson, 2006; Baker and Robertson, 2008; Henz, 2009; Sandberg and Erkisson, 2009). Findings to date suggest that women tend to engage in more emotional and day to day care, while men provide supervisory and monetary caring inputs (O'Connor and Ruddle, 1988; Collins and Jones, 1997; Chappell and Parmenter, 2005; Hooyman and Kiyak, 2008; Zabalegui et al, 2008). Similarly, a study by Pretorius, Walker and Heyns (2009) found that effective male informal dementia carers were found to use task-oriented approaches to solve problems and make efficient use of supports. The reasons for gender differences have not yet been comprehensively examined. However, potential explanations might relate to the influence of traditional gendered roles and socialisation (Pretorius, Walker and Heyns, 2009). Importantly, informal carers can also include friends or neighbours (Vitaliano, Zhang and Scanlan, 2003), particularly where relatives may be distant or absent. In a recent Irish survey, 1.7% of carers described themselves as a neighbour, friend or other (Care Alliance, 2008). The increasingly

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[20] It is noteworthy that there is no single unified definition of the term 'family carer'. This can sometimes complicate comparison across and between research findings.

heterogeneous nature of informal carers is consequently now recognised (The Carers Association, 2008). This implies that future research will need to include non-kin carers, as more and more "friends and families of choice become part of the caring network" (Victor, 2005: 276).

3.5 The nature, process and impact of informal dementia care[21]

Even though related research has grown exponentially over the past three decades, due to the complex and multi-dimensional nature of informal dementia care, no single interpretation and/or model has been constructed to explain the concept in its totality (Keady et al, 2007; Zabalegui et al, 2008). It is doubtful that it is even possible to do so. However, conceptual and theoretical approaches are required to understand the dimensions of care, particularly in societies experiencing social alteration (Philips, 2007). To date, a variety of lenses have been applied using various disciplinary and theoretical perspectives (Pearlin et al, 1990; Adams, 1996). While this can make synthesis difficult, it is through this research that current understandings of informal dementia care are constructed. This literature will be explored with reference to the following:

3.5.1 Informal dementia care: related activities,
3.5.2 Informal dementia care: impacts and consequences,
3.5.3 Informal dementia care: burden, stress, appraisal and coping perspectives and
3.5.4 Informal dementia care: a dynamic and temporal process.

3.5.1 Informal dementia care - related activities

Traditionally, informal dementia care was constructed in terms of the instrumental activities engaged in by carers. These were frequently described in terms of the incumbent tasks, including assistance with activities of living (basic and/or instrumental), and care was understood to be generally homogeneous (Ray, Bernard and Philips, 2009). Related research frequently employed surveys and used categories or lists of the components of care (for example: Parker and Lawton (1994), Zhue, Moore and Clipp (2003) and Brouwer et al (2005)). Pearlin et al (1990) describes these as the behavioural activities and experiences provided to those unable to provide them for themselves. As progression of dementia is accompanied by alterations to functional ability and an increase in related needs, interest in informal caring activities is not surprising. However, policy and professional interest in the instrumental

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[21] The literature associated with this section is vast and it would not be possible to include it all. Therefore, a representative sample will be included with particular reference to seminal or particularly illustrative writings relating to each sub-section.

components of informal care could also stem from the influence of the demography and medical discourses on dementia (Chapter 2, Sections 2.3.1, 2.3.3). Similarly, Victor (2005) indicates that the measurement of caring tasks could be used to indicate the need for formal services where informal carers are unable to continue to care without supports.

However, focusing solely on the physical activities of dementia care is limiting and a distraction from the many other aspects of the role (Bowers, 1987). This is because knowledge of instrumental tasks does not elucidate the essence of living with dementia, which Svanstrom and Dahlberg (2004) describe as a heteronomous existence focused on daily coping. Neither does it comprehensively explain what constitutes the components and associated meanings of the less visible aspects of caring-related activities. The lack of early theorising about such aspects of informal care has been highlighted (Ray, Bernard and Philips, 2009). In consequence, less task focused lenses have been employed to explore informal caring, such as grounded theory and phenomenological approaches. In one such early study, Bowers (1987) illuminated five aspects of informal dementia care: anticipatory care-giving (actions or decisions on potential parental needs), preventive care-giving (pre-emptive actions designed to prevent complications or progressions), supervisory care-giving, instrumental care-giving and protective care-giving (from the potential consequences of threats to self-perception). Interestingly, carers considered instrumental caring tasks the least important component. Nolan, Grant and Keady (1996) later re-conceptualised and extended Bower's (1987) work to provide a comprehensive alternative with which to de-emphasise instrumental components of care. They added the following categorisations: (re)constructive care (focused on rebuilding identity with reference to biography and goal substitution) and reciprocal care (referring to the reciprocity arising within and satisfactions derived from caring).

The centrality of the intent of caring actions was also indicated by Caron and Bowers (2003). In this study, care-giving purpose was conceptualised in terms of: inter-relational caring (directed towards maintaining sense of self in the recipient of care and preservation of the carer-cared for relationship) and pragmatic caring (ensuring that the care recipient was physically and emotionally comfortable and shifts to sharing care with formal services). The findings also highlighted the importance of promoting personhood. Personhood is a fundamental component of many models of dementia care (Kitwood, 1997; O'Connor et al, 2007; Dewing, 2008). However, it is suggested that personhood can only be supported through relationships and nurturing social environments (Brooker, 2007). Gates (2000) elucidated a structural definition of informal care to support personhood, which included (among other factors): poignant remembering to facilitate meaning-making, steadfastness across the continuum of care and the giving of nurturing care which promotes quality of life for the person with dementia. Perry and O'Connor (2002) further identified four strategies used by spouses to preserve personhood:

- maintaining continuity between the past and the present by ensuring understanding of the person with dementia and interpreting current actions in relation to previous ways of being,
- supporting the current abilities of the person with dementia by focusing on strengths,
- protecting from incompetence by ensuring that situations in which lost abilities might be encountered were avoided and
- strategising encounters by either avoiding contexts in which the person with dementia's sense of self could be compromised or by ensuring social interactions were comfortable.

Less focus has been afforded to the components of informal care in early dementia. Recognising this, Betts Adams (2006) explored the transition to care-giving of 20 spouses and daughters of persons with early dementia or mild cognitive impairment. Participants described progressive accommodation of impairment-related changes, assuming multiple new responsibilities (including, household and instrumental tasks and being an emotional cheerleader for the person with dementia), decision-making (relating to when to intervene and safety) and supervision. Help seeking was referred to but avoided in this study; perhaps because of the early stage of dementia. However, other studies identify information seeking and accessing supports, as important over the course of caring (Quayhagen and Quaghagen, 1988; Wilson, 1989a; Butcher, Holkup and Buckwalter, 2001; Morton, 2003; Galvin, Todres and Richardson, 2005). In Betts Adams (2006) research, participants also referred to the emotional components of caring, including: frustration, relational deprivation, protectiveness and tenderness directed towards the person with dementia. Similar emotional reactions, including guilt, are reported in other dementia care research (Ching-Ching Chung, 1997; Butcher, Holkup and Buckwalter, 2001; Perry and O'Connor, 2002; Galvin, Todres and Richardson, 2005).

This section has demonstrated that while the elucidation of the related activities of informal dementia care is important to understanding the phenomenon, focusing only on these can detract from indirect care, which includes the: planning, organising, mediating, monitoring and supervising aspects (Given and Given, 1991). Alternatively, exploring the wider components of informal dementia care using broader lenses has added to greater understanding of what is entailed. Related research could be suggested to extend the relational discourse on dementia (Chapter 2, Section 2.3.5) to the phenomenon of informal dementia care. Informal care may thus be conceptualised in terms of: 'caring for' (instrumental/pragmatic caring), 'caring about' (expressive or emotional caring) (Dalley, 1996; Jansson, Nordberg and Grafstrom, 2001; Victor, 2005) and in some cases 'caring with' (Hellstrom, Nolan and Lundh, 2007). However, an over-emphasis on ‘caring for’ is inadequate (Lane et al, 2000). This is because it could threaten the “integrity of the whole” (Woodward, 1997: 999). Researchers have consequently turned to the wider processes of care. This research does not limit its focus to the components of informal dementia care. Instead, it illuminates: the impact and consequences of caring, ways of coping, the inter-relational nature of the carer/care-recipient dyad and related caring actions over time. This research will be explored in the following sections.

3.5.2 Informal dementia care – impacts and consequences

The outcomes of informal dementia care tend to be constructed negatively and are generally portrayed as time consuming, at times unpleasant and psychologically and physically stressful and exhausting (Schulz and Martire, 2004). However, an alternative or more specifically a co-existent but less recognised construction also exists, which addresses the rewards and benefits of informal dementia care. This section will explore the literature relating to both of these constructions of informal dementia care.

3.5.2.1 Impacts on time, family, social and employment involvement

Informal dementia care is understood to be inherently time consuming, reducing time for oneself, family, social or occupational activities (Zarit, Reever and Bach-Peterson, 1980; Lindgren, 1993; Ching-Ching Chung, 1997; Ory et al, 1999; Borrayo et al, 2007). This is referred to as ‘role captivity’ by Aneshensel et al (1995: 95) and ‘role engulfment’ by Skaff and Pearlin (1992: 657). The time involved in informal dementia care has been shown to particularly relate to problematic behaviours and functional limitations in the person with dementia (Moore, Zhu and Clipp, 2001; Zhu, Moore and Clipp, 2003). The ensuing social consequences frequently result in isolation and/or social restriction or deprivation (Pearlin et al, 1990; Willoughby and Keating, 1991; Skaff and Pearlin, 1992; Almberg, Grafstrom and Winbald, 1997a; Connell, Janevic and Gallant, 2001; Papastavrou et al, 2007; Andren and Elmstahl, 2008). This is because informal carers can experience increasing difficulty in maintaining social contacts, interests and family relations. Lack of independence and time for self has in turn been associated with affecting quality of life and a sense of hopelessness (Chappell and Reid, 2002; O'Shea, 2003; Svanstrom and Dahlberg, 2004; Vellone et al, 2008). Importantly, freedom here relates not only to time to do things, but also time to think and pursue wants (Vellone et al, 2008). Family conflicts/difficulties are also reported (Fudge, Neufeld and Harrison, 1997; Almberg et al, 1998; Wimo, Winbald and Grafstrom, 1999; Neufeld and Harrison, 2003; Farran et al, 2004; Zabalegui et al, 2008). Pearlin et al (1990) identify three such conflicts: dementia impairment related issues, disagreement about how much attention family members give to the person with dementia and attention given to the carer for their caring role.

The financial impacts of informal care have also been shown to result in strain (Quayhagen and Quaghagen, 1988; Ory et al, 1999; Kolanowski et al, 2004). Three types of economic costs are highlighted: unpaid labour, out of pocket expenses and employment related costs (lost income and/or benefits and reduced later financial well-being) (Fast, Williamson and Keating, 1999; McGarry, 2006). In Ireland, O'Shea (2003) found that two-thirds of informal carers reported financial strain and the same percentage reported alterations to work patterns and schedules to facilitate caring. Clearly, while some may want to combine caring with a paid work role, the freedom to choose can become restricted as dementia progresses (Skaff and Pearlin, 1992; Aneshensel et al, 1995; Walker, Pratt and Eddy, 1995; Arksey and Glendinning, 2007). Where informal carers do combine caring with paid employment, Edwards et al (2002) have found that job conflict was linked to increased role strain and depressive symptoms. However, when examined, statistical differences did not occur in terms of role strain between employed and non-employed informal carers. The recognition of the potential impact of informal care on the ability to engage in employment has resulted in initiatives to support informal carers, including flexibility in work arrangements and unpaid leave policies (Colello, 2007). For example, Irish informal carers may be eligible for Carers Leave and a Carers Benefit payment. Social insurance credits are made for those in receipt of this benefit to protect pension and future social welfare entitlements. However, these schemes are noted to be restrictive and limited in their potential for support (O'Shea, 2003). At a macro level, the financial costs of informal care also impact on the labour market. This is related to the potential impacts on productivity due to loss of skilled workers, particularly when an ageing society will result in a falling ratio of those in employment to those retired (McGarry, 2006).

3.5.2.2 Impacts on informal carer-person with dementia relationships

Over time, dementia progression increasingly impacts on the relationship between the informal carer and person with dementia. Hayes, Boylstein and Zimmerman (2009) found that intimacy (social, emotional, physical and sexual) can be affected between spousal carers and persons with dementia, but not always in negative ways. They suggest this may in part relate to alterations in social interaction and interpersonal engagement that can occur in dementia. Interestingly, these researchers also suggested gender differences, with caring and intimacy experienced differently by women and men. Loss of intimacy with progression of dementia has also been cited by Butcher, Holkup and Buckwalter (2001). Research demonstrates that many informal carers work to maintain relationships with the person with dementia (Caron and Bowers, 2003). Other research has demonstrated that this is not one sided because although the nature of relationship may increasingly fragment, many couples actively work together to sustain their relationships for as long as is possible (Hellstrom, Nolan and Lundh, 2007). However, grief and loss reactions have also been demonstrated in the presence of dementia. Around the time of diagnosis, many carers identify a grief reaction to the loss of a life previous to the intrusion of dementia (Perry, 2002; Kolanowski et al, 2004; Betts Adams, McClendon and Smyth, 2008).

As dementia advances, the nature of relationships continues to change. There can be a progressive loss of reciprocal intimacy and companionship between the informal carer and person with dementia (Pearlin et al, 1990; Betts Adams, 2006). This can lead to an ongoing appraisal of: relational losses of elements essential to a connection with the person with dementia, psychological losses and ongoing grief (Willoughby and Keating, 1991; Aneshensel et al, 1995; Adams, 1996; Montgomery and Williams, 2001; Betts Adams, 2006; Betts Adams, McClendon and Smyth, 2008). Butcher, Holkup and Buckwalter (2001: 45) refer to this as "a sad and extended leave-taking from the people they once were" and Morris and Morris (2010: 98) to a "slow grieving process". Such grief has been conceptualised as social death in advance of biological death (Garner, 1997). However, Sweeting and Gilhooly (1997) found that although their respondents believed the person with dementia was somewhat socially dead, they behaved as if they were alive. Grief is also disenfranchised during this time as the loss is not subject to the recognition and support normally accompanying biological death (Doka, 2004). For example Morton (2003: 266), an informal carer of her husband with dementia, referred to herself as being in an "ambiguous status of unofficial widow". Following the death of a person with dementia, Aneshensel et al (1995) and Zarit and Gaugler (2006) identify the bereavement process as a critical transition in caring. However, little is known about this or about how previous caring may affect adaptation to the actual loss, even though there is some suggestion that pre-existing loss may act as a psychological preparation for physical and caring role losses (Aneshensel et al, 1995).

3.5.2.3 Impacts on mental and physical health

The time available to care for one's health is much reduced when caring for a loved one with dementia (Son et al, 2007; Vellone et al, 2008). Research suggests that informal carers are at risk of negative health outcomes when compared to non-dementia carers (Ory et al, 1999; Pinquart and Sorenson, 2003). The resultant morbidities are broad and may increase with prolonged caring. Findings have resulted in some consensus that the following mental health issues may occur: exhaustion, distress, strain, depression, anxiety and fatigue (Aneshensel et al, 1995; Schulz et al, 1995; Zanetti et al, 1998; Ory et al, 1999; Gaugler et al, 2000; Vedhara et al, 2000; Gallicchio et al, 2002; O'Shea, 2003; Brouwer et al, 2005; Borrayo et al, 2007; Cooper et al, 2007). However, research also demonstrates that the impact on individual mental health may vary (Connell, Janevic and Gallant, 2001). For example, spousal carers have been found to have greater depression and stress, and lower life satisfaction in relation to other family carers (Schulz et al, 1995). Mental health outcomes have also been linked to the impact of ongoing and/or increasing exposure to stressors such as: increases in disability, dependency and behaviours that challenge (Quayhagen and Quaghagen, 1988; Skaff and Pearlin, 1992; Grafstrom, Fratiglioni and Winbald, 1994; Gaugler et al, 2000; Raina et al, 2004; Papastavrou et al, 2007). In contrast, Zanetti et al (1998) found that it was carer-related factors (relationship, health and competence) that independently predicted depressive symptoms. Similarly, recent research indicates that social embarrassment is significantly related to informal carers' self-reported depression (Montero-Rodriguez et al, 2009). Gender differences are also identified (Given et al, 1999; Raschick and Ingersoll-Dayton, 2004; Pretorius, Walker and Heyns, 2009). Related research suggests women have worse mental health outcomes than men (Walker, Pratt and Eddy, 1995; Collins and Jones, 1997; Almberg et al, 1998; Pinquart and Sorenson, 2003; Thompson et al, 2004; Pinquart and Sorenson, 2006; Thomas et al, 2006; Papastavrou et al, 2007). However, the reasons for this have yet to be comprehensively explored.

In relation to physical health status and overall well-being, there is evidence to support the hypothesis that these can also be negatively affected by caring (Quayhagen and Quaghagen, 1988; Fast, Williamson and Keating, 1999). Negative health symptoms have been reported as increasing by 33% following the assumption of caring (Shanks-McElroy and Strobino, 2001). Specific physical health effects that have been illustrated in men and women include: alterations in cellular immunity (Mills et al, 2004), aspects of cardiovascular functioning such as hyperlipidaemia and hyperglycaemia (Vitaliano, Russo and Niauro, 1995), increased stress hormones (Vitaliano, Zhang and Scanlan, 2003) and hypertension (Knight et al, 2007). Research also suggests that the physical effects of informal care may relate to increased depression (Montero-Rodriguez et al, 2009). As with mental health consequences, women carers have reported worse subjective physical health (Pinquart and Sorenson, 2006; Zhang, Vitaliano and Lin, 2006). It is further suggested that informal caring could pre-dispose carers to engage in risky health behaviours, for example: inadequate nutrition, sedentary lifestyles or substance abuse (Connell, Janevic and Gallant, 2001; Vitaliano, Zhang and Scanlan, 2003). However, contradictory findings abound (Schulz et al, 1995; Connell, Janevic and Gallant, 2001). Some research suggests little or no difference in physical health or health care utilisation when informal carers are compared with non-carers (Almberg et al, 1998; Moore, Zhu and Clipp, 2001; Pinquart and Sorenson, 2006). For example, Kolanowski et al (2004) found that over a three year period, spousal carers appeared to be healthier than matched comparison spouses. In addition, Vitaliano, Zhang and Scanlan's (2003) meta-analysis, comparing the health status of informal dementia carers with non-carers, found that in the eleven health categories compared, informal carers demonstrated only a slightly greater risk for a variety of health issues.

The research exploring the impact and consequences of informal care above constructs the informal carer as a person "effectively pathologized by their need ... a carer above all other aspects of their lives" (Ray, Bernard and Philips, 2009: 118). Thus, similar to the medical discourse on dementia, informal care can be subject to the surveilling processes of medicine and mental health (Chapter 2, Section 2.3.3). The affect of this tendency to pathologise care-giving has resulted in the creation of a primarily negative picture of caring (Nolan, Grant and Keady, 1996). Constructing the phenomenon in this manner may in turn add to the fear of dementia discussed in Chapter 2 (Section 2.3.4). However, Given and Given (1991) and others suggest that it is an assumption that caring is an arduous burden with only negative impacts and consequences. The research supporting this position will now be explored.

3.5.2.4 Benefits and rewards of informal care

Concentrating solely on the negatives of informal caring creates an unequal and incomplete image of the phenomenon (Butcher, Holkup and Buckwalter, 2001). In contrast, there is a burgeoning literature contending that informal dementia care is not entirely the negative experience that it is almost always portrayed to be. For example, McConaghy and Caltabiano (2005) found that satisfaction with life was not reduced over time for informal carers of persons with dementia. Andren and Elmstahl (2005) and Netto, Goh and Yap (2009) found that care related burden and satisfaction can co-exist. In Grant and Nolan's (1993) study, 60% of respondents identified sources of rewards and satisfactions. Farran et al (1991) and Butcher, Holkup and Buckwalter (2001) further reported that 90% and 78% respectively of their samples referred to the positives of caring. This and other research suggests the following specific caring benefits and/or rewards: a sense of mastery, pride, expertise, competence, relationship gains, personal growth, self-gain, meaning-making, uplifts, joy, satisfaction and gratification (Powell Lawton et al, 1991; Skaff and Pearlin, 1992; Walker, Pratt and Eddy, 1995; Kramer, 1997; Farran et al, 1999; Butcher, Holkup and Buckwalter, 2001; Hunt, 2003; Lewis et al, 2005; Netto, Goh and Yap, 2009). However, differences in benefits and rewards have been identified between informal carers. For example, Raschick and Ingersoll-Dayton (2004) found that adult children experienced more rewards when compared with spousal carers. However, these findings did suggest that care-recipient helpfulness increased the likelihood of greater rewards for spousal carers. Although not dementia specific research, satisfaction with caring has also been significantly related to the gender of the person receiving care, with higher satisfaction more likely when caring for a woman, irrespective of the informal carer's gender (Grant and Nolan, 1993).

While conceptually distinct, the potential interaction between the positive and negative aspects of informal caring has also been identified. For example, care-giving satisfaction has been found to relate to positive affect (Powell Lawton et al, 1991), older age and perceived social support (Harwood et al, 2000). Care-giver gain has also been suggested to affect the relationship between stress and negative affect (Rapp and Chao, 2000). Hence, Brouwer et al (2005) suggest that focusing only on the negative aspects of care could undervalue the overall process, but recognise that some carers are overly burdened and would benefit from others taking over care tasks. Clearly, informal caring can have a mixed value (Pearlin et al, 1990; Powell Lawton et al, 1991; Grant and Nolan, 1993; Raschick and Ingersoll-Dayton, 2004). Research has also suggested that satisfaction in caring is related to more qualitative factors in or around the carer-care-recipient dyad than the dependency of a care recipient (Grant and Nolan, 1993). Related research found that the nature of past relationships was significant, with satisfaction evident particularly where positive pre-existing relationships occurred. Similarly, in Motenko's (1989) study of informal caring wives, those who reported durability in the degree of closeness had greater gratification from caring and demonstrated better well-being. Thus informal care while difficult, is also "about human commitment, care, warmth, love and devotion" (Keady and Braudy Harris, 2009: 5). An understanding of the positive aspects of informal care and caregiver gain is clearly a pre-requisite to a comprehensive understanding of the overall construct (Given and Given, 1991; Kramer, 1997; Raschick and Ingersoll-Dayton, 2004; Helmes, Green and Almeida, 2005; Innes, 2009). This could also enhance: knowledge of informal carer strengths, means by which to increase positive aspects of care and recognition of those carers less likely to need intervention (Kramer, 1997; Farran et al, 1999; Connell, Janevic and Gallant, 2001; Netto, Goh and Yap, 2009; Ray, Bernard and Philips, 2009).

Methodological differences across studies exploring the impact and consequences of informal care make it difficult to compare findings. For example, the use of self-administered inventories in contrast to standardised measures of morbidities (Schulz et al, 1995) and convenience and not random sampling. Pinquart and Sorenson (2006) further highlight the dearth of detail relating to findings; for example if gender differences are statistically and/or practically significant when averaged across studies. Questions have also arisen, as to whether psychometric instruments can include the entire repertoire of costs and gains (Kramer, 1997). The literature does though suggest that the same demands can result in different consequences for informal carers, with some coping well and others not (Montgomery and Williams, 2001). Walker, Pratt and Eddy

(1995: 405) consequently ask if informal caring is both "relentless and potentially overwhelming", why does it not uniformly result in negative outcomes for carers? It is suggested that carer personality and/or individual characteristics may account for some of these differences (Almberg, Grafstrom and Winbald, 1997a; Helmes, Green and Almeida, 2005). This research will now be explored.

3.5.3 Informal dementia care – burden, stress, appraisal and coping perspectives

A great majority of the informal carer research has emphasised informal dementia care as a psycho-social process (Adams, 2002). The negative impacts and consequences of informal care highlighted in section 3.5.2 have been associated with such burden (Almberg, Grafstrom and Winbald, 1997a; Bramble, Moyle and McAllister, 2009). A number of models have consequently emerged that view burden and stress as central to the construction of informal dementia care and ways of coping (Pearlin et al, 1990; Borrayo et al, 2007). These burden and stress-coping perspectives suggest that informal carers cope in individual ways that are mediated by identifiable variables, which in turn affect carer outcomes.

3.5.3.1 Burden models

As burden (subjective and objective) is identified as a significant psycho-social response to informal dementia care, much research has been conducted to explore its effect on well-being (Quayhagen and Quaghagen, 1988). Given and Given (1991: 84) refer to burden as the "bio-psycho social reaction of the primary caregiver resulting from an imbalance of demands relative to resources available". It is suggested that burden can occur when informal carers are unable to modify their strategies to meet caring demands (Given et al, 1999). The identification of burden and its contributing factors is important, as informal carers with lower burden have reported better health (Andren and Elmstahl, 2008). It could also enable the design of tailored interventions to prevent and/or treat the associated negative health impacts.[22] Research has suggested that burden affects overall carer well-being (McConaghy and Caltabiano, 2005). For example, informal carers of persons with dementia have demonstrated higher levels of physical burden and distress when compared with other carers (Kim and Schulz, 2008). Andren and Elmstahl (2008) found that 57% of their sample reported a medium burden level and 5% reported high burden levels, with close relative carers demonstrating higher burden. Almberg, Grafstrom and Winbald (1997a) further suggested that informal dementia carers with poor

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[22] Related concerns have led to the development of scales to measure the construct in informal dementia carers (Zarit, Orr and Zarit, 1985; Grafstrom, Fratiglioni and Winbald, 1994; Almberg, Grafstrom and Winbald, 1997a; Bedard et al, 2001; Papastavrou et al, 2007).

health, restricted social life and a poor outlook on the care situation were more prone to burden and burnout. Informal carer burden has also been related to gender, with women at higher risk (Grafstrom, Fratiglioni and Winbald, 1994; Garity, 1997; Papastavrou et al, 2007; Ulstein, Bruun Wyller and Engedal, 2007).

Behavioural and psychological symptoms of dementia are frequently found to cause great difficulties in terms of informal carer burden (Chappell and Reid, 2002; Pinquart and Sorenson, 2003; Helmes, Green and Almeida, 2005). More specifically, Ulstein, Bruun Wyller and Engedal (2007) found that hours spent caring, difficulties in activities of living and high Neuropsychiatric Inventory scores (measuring psychopathology, including: delusions, hallucinations, dysphoria etc.) were significant in terms of social distress. They additionally found that high levels of behavioural and psychological symptoms and hours caring were significant in terms of emotional distress. Papastavrou et al's (2007) study similarly demonstrated high burden levels that positively correlated with problem behaviours and only weakly associated with cognitive impairment. Interestingly, in comparing informal care for younger persons with dementia with care for older persons with dementia, burden has not been found to be greater (Arai et al, 2007). However, difficulties with behaviours that challenge were found to be greater in younger persons (Arai et al, 2007). In relation to the demands of caring, Given et al (1999) identified that informal carers experiencing new demands had higher levels of depression (an outcome of burden) than carers experiencing similar demands but for longer periods of time. This finding is partially supported by McConaghy and Caltabiano (2005) who illustrated that consistent caring over an extended time period was linked with lower burden levels. In relation to the context of caring, some research suggests there is little or no difference in informal carer burden levels whether the person with dementia lives in the community or in continuing care (Almberg, Grafstrom and Winbald, 1997a; Papastavrou et al, 2007). This might be considered a surprising finding in light of the demands of caring in the community and as such would benefit from further exploration.

Studies of burden have some methodological weaknesses (Ulstein, Bruun Wyller and Engedal, 2007). In their important meta-analysis, Pinquart and Sorenson (2003) demonstrated that burden was more strongly associated with stressors and caring uplifts in probability rather than convenience samples (most studies). The use of multiple scales further complicates comparison and conflicting findings are problematic. For example, contrasting with the findings reported above, some research does not or only tenuously supports the hypothesis that physical impairment and functional level of the person with dementia is related to carer burden (Montgomery and Williams, 2001; Pinquart and Sorenson, 2003). Several studies additionally found no relation between the degree of behavioural difficulties and carer burden (Zarit, Reever and Bach-Peterson, 1980; Collins and Jones, 1997). In relation to depression, Zanetti et al (1998) highlighted that it was carers' personal resources and physical health and not care recipient factors that were the main independent risk factors. The actual utility of carer burden has also been questioned (Given and Given, 1991). Research by Chappell and Reid (2002) suggests that a focus on quality of life may be more helpful because even in the presence of burden, quality of life may be improved. So even though knowing how burden can contribute to ill-health is important, it is a global concept and Pearlin et al (1990) suggest that there is a consequent need to disaggregate its composite stressors.

3.5.3.2 Stress-appraisal-coping models

Informal dementia care is frequently constructed as a "chronically stressful experience that poses significant adaptive challenges" (Gottlieb and Wolfe, 2002: 325). Much of the related research is guided by an understanding of stress as a process (Lazarus and Folkman, 1984; Pearlin et al, 1990; Aneshensel et al, 1995; Hunt, 2003). This is one of the dominant approaches to the study of informal dementia care. The stress-process model devised by Pearlin et al (1990) and Aneshensel et al (1995) underpins much of the available research. This model emphasises four domains (each with multiple components) and the inter-relationships among them over time: 1. background and context, 2. stressors (primary and secondary), 3. resources/mediators of stress and 4. health outcomes (depression, anxiety, physical and mental health changes and withdrawing from the caring role) (McKean Skaff, Pearlin and Mullan, 1996; Montgomery and Williams, 2001). Related research infers coping may differ among individuals and that the outcomes of caring are subject to two mediating variables (Farran et al, 1991). Firstly, social support (formal and informal) and satisfaction with it may lessen perceptions of burden due to the emotional, practical and information supports provided (Connell, Janevic and Gallant, 2001). Secondly, coping as it is suggested that the model incorporates aspects of the transactional stress-coping model of Lazarus and Folkman (1984). Here, cognitive appraisal of the ability to cope with a stressor, appraised as exceeding personal resources, can lead to either active problem-focused coping (designed to directly address the stressor) and/or emotion-focused coping (to ameliorate emotional distress). Okabayashi et al (2008) also refer to a third coping strategy - appraisal focused coping. This coping strategy relates to the definition and redefinition of the meaning of a situation to an individual (Billings and Moos, 1984). Okabayashi et al (2008) suggest that these three coping strategies correspond to some degree with Pearlin et al's (1990) management of situation (problem focused coping), management of self (emotion focused coping) and management of meaning (appraisal focused coping).

Viewed through a stress-coping lens, informal care for persons with dementia involves cognitive, affective and behavioural reactions by carers. According to Gottlieb and Wolfe (2002: 325), these reactions are intended to "regulate their [informal carers] emotions, solve or improve the practical problems they face, and maintain the psychological resistance and fortitude needed to stay productively engaged in caregiving". George (2005: 292) refers to the stress-process model as "simple but elegant". As a heuristic to dementia care research, it is well supported with empirical evidence and has been used to inform research investigating the relationships between caring and carer health (Raina et al, 2004). For example, Son et al (2007) demonstrated that high levels of stressors (behaviours that challenge and perceived overload) were related to three informal carer health dimensions: poorer self-reported health, increased negative health behaviours and health service usage. Research has also demonstrated that the amount of care and other care recipient factors (physical and cognitive, as well as behavioural difficulties) relate to burden and that the impact of these factors on mental and physical health are mediated by carers' appraisal of burden and by resources (coping styles and social support) (Pearlin et al, 1990; Aneshensel et al, 1995; Pinquart and Sorenson, 2003; Knight et al, 2007).

The model has been amended by some researchers (Yates, Tennstedt and Chang, 1999; Chappell and Reid, 2002), with later research focusing on these resources in terms of their moderating or buffering effects (George, 2005). This research demonstrates that practical forms of active or problem focused coping may relate to better well-being (George, 2005; McConaghy and Caltabiano, 2005). Such findings are supported by Almberg, Grafstrom and Winbald (1997b), who compared informal carers of persons with dementia experiencing burnout (group a) with those who were not (group b). They found that burnout was linked with the use of some emotion focused strategies, including: grieving, worrying and self-accusation. Problem-focused coping strategies, including: problem confrontation and the seeking of information and social support were more common to carers not demonstrating burnout (Almberg, Grafstrom and Winbald, 1997b). Interestingly, the use of certain emotion focused strategies (such as acceptance) in tandem with problem focused coping were found to be effective in group b. This suggests that it is the choice of emotion focused coping strategy and not emotion focused coping per se that is important. More recent research has again shown that problem focused coping and seeking social support are linked to lower burden, while certain emotion focused coping strategies, such as wishful thinking, are linked to stress (Papastavrou et al, 2007).

Mastery has recently been identified as a psychological resource, with lower mastery enhancing reported losses, increased role overload and depression symptoms (Betts Adams, McClendon and Smyth, 2008). Interestingly, Mc Kean Skaff, Pearlin and Mullan (1996) found that mastery is not fixed; it decreases the longer caring continues, remains stable when a person with dementia enters continuing care and increases following the death of the person. A different modification of the stress process, centralising carer appraisal, was developed by Powell Lawton et al (1991). This model was tested in relation to caring transitions of daughter carers and suggested informal carers' quality of life did not decrease over time (Powell Lawton et al, 2000). Therefore, the findings of the study provide little support for a wear and tear theory of caring, in which it is hypothesised that caring competencies and mental and physical health decline over time in the informal carer. However, the findings do suggest support for an adaptation hypothesis, wherein quality of life is sustained in the presence of increasing stressors (Powell Lawton et al, 2000). Further studies were however advised.

The medicalising of informal carer roles, as burdensome and stress inducing, has led to interventions to ameliorate such conditions (Bond, 1992). There are a number of systematic reviews and/or meta-analyses of the available research. These demonstrate varied results due to intervention studies utilising small informal carer numbers and methodological factors including varied intervention approaches and descriptions (Cooke et al, 2001; Brodaty, Green and Koschera, 2003). Carretero et al (2009) divide the interventions into two types: respite (day care, home help and extended respite stays) and psychosocial intervention programmes (psychological interventions, education, information provision, counselling, help groups etc). The reviewers conclude that a combination of approaches, in particular respite and psycho-education, may lessen burden and equip informal carers with knowledge, skills and strategies to cope. Cooke et al (2001) examined the success of psychosocial and psycho-educational interventions for informal dementia carers and found that over two thirds of the interventions showed no improvements in outcomes. Those studies that did demonstrate a positive effect involved interventions that incorporated social support or social components in tandem with cognitive aspects such as problem solving. The findings of Acton and Kang's (2001) meta-analysis again demonstrated little or no effect collectively on carer burden, however multi-component interventions did lessen burden. As in the previous section, these researchers suggest that burden may be an overly global outcome measure and the development of more specific outcome measures is recommended. Brodaty, Green and Koschera's (2003) meta-analysis employed a number of such outcome measures. Once again varied results were shown. However, these researchers did highlight greater success where persons with dementia were included in interventions and they recommended that programmes should be intensive and individualised. Zarit and Leitsch (2001) further call for original interventions, underpinned with a rigorous scientific approach to their design and evaluation, as to date this has been lacking.

While the stress-coping research has much to offer, its design needs to be sound and the outcomes need to inform practice (Gottlieb and Wolfe, 2002). Many studies investigate only one stressor type on single health measures (Son et al, 2007). Interpretation of questions or scale items can also be subject to interpretive differences and there can be difficulties with single measures, as change over time is not reflected (Victor, 2005). Much of the research relies on scale items presumed important by researchers. However, the relative importance of such items to informal carers cannot be assumed. Many of the burden/stress approaches also fail to consider the importance of context (Farran, 1997; Dilworth-Anderson, 2001; Montgomery and Williams, 2001; Gottlieb and Wolfe, 2002; Nolan et al, 2003). Therefore, while the research exploring burden, stress, appraisal and coping in informal dementia care enhances understanding, Nolan et al (2003) highlight a paradigm shift directed towards more complete understanding of the phenomenon of such care. In consequence, researchers are increasingly turning to informal carers to construct a contextual understanding of informal dementia care over time.

3.5.4 Informal dementia care - a dynamic and temporal process[23]

Victor (2005) identifies the development of theoretical models relating to the timing of care needs based on illness severity, as an important way of constructing the informal care process. The associated literature constructs informal dementia care in terms of a subjective trajectory that changes with the passage of time (Table 3.1). These theories, which are derived from the narratives and direct experiences of informal carers and sometimes persons with dementia, demonstrate some commonalities. Each generally begins with a gradual recognition of dementia, moves through middle stage(s) characterised by intense multi-factorial caring involvement and ceases with ending of the role and movement towards a new start. This research is suggested to address a noticeable gap in understanding alterations in the caring experience over the course of dementia (Willoughby and Keating, 1991). Much of the research adopts a grounded theory approach and the findings are suggested to advance understanding, while highlighting researcher assumptions applied to, but inconsistent with, the actual world of informal dementia care experienced by informal carers (Bowers, 1987).[24]

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[23] Where relevant, aspects of the findings of the research reviewed in this and in preceding sections, will be compared and contrasted with components of the theory of 'Sustaining place' in chapters 6-9.

[24] When grounded theory is used, all of the resultant models are conceptualised to a substansive level. This literature review located no formal grounded theories of informal dementia care.

Table 3.1 Examples of temporal models of the informal caring process

Author	Year	Theory Stages
Wilson	1989a 1989b	1. Noticing 2. Discounting and normalising 3. Suspecting 4. Searching for explanations 5. Recasting 6. Taking it on (1989a) 7. Going through it (1989a) 8. Turning it over (1989a)
Willoughby and Keating	1991	Taking on and relinquishing control: 1. Emerging recognition 2. Taking control: making my own decisions 3. Losing control: accepting others decisions 4. Adjusting to the psychiatric institution 5. Moving on
Lindgren	1993	1. Encounter 2. Enduring 3. Exit
Wuest, King Ericson and Noerager Stern	1994	Becoming strangers: 1. Dawning 2. Holding on 3. Letting go
Aneshensel et al	1995	Caregiving career: 1. Pathways to care: Role acquisition 2. Perseverance and resignation: Role enactment 3. Grief and readjustment: Role disengagement
Perry	2002	Interpretive caring: 1. Seeing the signs <u>or</u> picking up the slack 2. Drawing new inferences 3. Taking over 4. Rewriting identities 5. Making daily life work

Keady and Nolan	2003	1. Building on the past 2. Recognising the need 3. Taking it on 4. Working through it 5. Reaching the end 6. A new beginning
Morton	2003	1. Denial – knowing something is wrong 2. Diagnosis – probable Alzheimer's 3. Acceptance – the swamp of confusion 4. Management (attempting control) – the sea of storms 5. Surrender (turning outward) – the dock of shock 6. Transformation – we to me 7. Feeling trapped – the cage of rage 8. Separation – finality, the bridge of separation
Hellstrom, Nolan and Lundh	2007	1. Sustaining couplehood 2 .Maintaining involvement 3. Moving on

In a study of 20 family members, Wilson (1989a) conceptualised informal dementia care as coping with negative choices. She described the three stage basic social process of 'Surviving on the Brink' (Table 3.1), which incorporated: uncertainty, ongoing demands, deficient supports and a dread of the future. The three stages in this theory were incorporated into a larger eight stage process (Table 3.1) in a second published article (Wilson, 1989b). Wilson (1989b: 44) suggested that by focusing on the lived experience of the informal carer, and not on the stages of dementia, a "patterned unfolding course" from the carer's perspective was discovered. The outcome of the study contrasts with a traditional emphasis on dementia pathology and related symptoms (Chapter 2, Section 2.3.3) and is supported by Morton (2003) who found that disease-related stages do not enable the carer to understand the processes they go through. In contrast to Wilson's (1989a, 1989b) research, which explored in-home carers with short experience, Willoughby and Keating (1991) conducted multiple interviews with family carers after placement in continuing care. In this study, informal care was conceptualised as pivoting around the five stage process of 'Taking on and relinquishing control' (Table 3.1) and relationships with others exemplified how carers coped with control related issues.

A number of studies conceptualise informal care in terms of a temporal career (McKean Skaff, Pearlin and Mullan, 1996; Powell Lawton et al, 2000). Lindgren (1993) developed five categories from carer data, which were cross categorised with three emergent periods of care-giving (early, middle and late). Comparison of the findings with the literature resulted in three stages of care-giving (Table 3.1). These encompassed learning, adaptation and restructuring of the carer's life. Aneshensel et al (1995) also portrayed informal dementia care as a career. The multistage sequential trajectory of the process was conceptualised as a "set of shifting configurations" relating to three distinct stages: role acquisition (recognising the need and role assumption), role enactment (engagement in tasks of informal caring, including the time after admission to continuing care) and role disengagement (ending of caring and a return to other facets of life following the death of a loved one) (Aneshensel et al, 1995: 17). This model differs to others as it emerged from a longitudinal study and incorporates the stress-process perspective addressed previously. It is also notable because most of the other studies did not follow a cohort over the course of the informal dementia care process.

The interactive process of "Becoming strangers" (Wuest, King Ericson and Noerager Stern, 1994) is also novel. It elucidates the reciprocal experience of dementia between the informal carer and/or family unit and the person with dementia over time. This three stage overlapping process (Table 3.1) is experienced as a continuum from intimacy to alienation and is mediated by commitment, insidious losses and connected or disconnected support. Focusing specifically on wives, Perry's (2002) study also conceptualised the relational nature of the informal caring process, naming it 'Interpretive caring' (Table 3.1) designed to maintain both persons in the dyad. However, contrasting with other more negatively oriented findings, 'Interpretive caring' was conceptualised as neutral allowing for the positive as well as negative components of the process (Perry, 2002). Relationality is also evident in Morton's (2003) personal account of her experience of informal dementia care as an eight phase journey taken with her husband who had Alzheimer's disease (Table 3.1) and Caron and Bower's (2003) earlier cited work.

Recent research has advanced many facets of these temporal process models. Two such studies are noteworthy. Keady and Nolan's (2003) well regarded six stage process (Table 3.1) builds on a previous version (Nolan, Grant and Keady, 1996), which in turn arose out of Keady's (1999) elaboration of Wilson's (1989a, 1989b) work. Although arising from dementia specific research, it has been empirically tested in non-dementia specific contexts adding to the trustworthiness of its structure. Different types of 'work' proactively undertaken by the person with dementia and the carer are central, particularly in the early stages of the theory. Thus, the writers elaborate on: working together, working alone, working separately and working apart (Keady and Nolan, 2003). Hellstrom, Nolan and Lundh (2007) drew on this work in their grounded theory of 'Sustaining couplehood'. Their three stage process (Table 3.1) was conceptualised as temporally-related but not necessarily linear "involving a delicate interactive and iterative relationship" (Hellstrom, Nolan and Lundh, 2007: 391). (This fluid non-linearity was also important in Caron and Bower's (2003) findings.) A strength of Hellstrom, Nolan and Lundh's (2007) approach, similar to Aneshensel et al's (1995), is that the process emerged over five data collection points in time, as repeated interviews were held with persons with dementia and informal carers.

There are a number of benefits from the temporal construction of informal dementia care. These include: enhanced understanding of the complexity of informal caring over time, acknowledgement that informal care is not static, that there are cognitive, affective and behavioural implications for carers over the progressive course of the disability and the potential to devise stage or phase specific policy and service interventions to support carers. This research also demonstrates that informal care in tandem with dementia can be discursively constructed in terms of an inter-relational experience (Chapter 2, Section 2.3.5). With one exception (Hellstrom, Nolan and Lundh, 2007), the theories referred to above generally represent an onward linear process associated with dementia progression. However, not all of these theories necessarily consider barriers or disruption to forward movement and what would then happen. In well developed theories, the mechanisms of transition between each stage are elucidated. This is not always the case though and could lead to a perception of incompleteness as the reader wonders how and why a carer transitions from one stage to the next. Similarly, there is not always reference to how long each stage will take or if each stage is experienced in the same way by all carers. One would imagine that the experience would be somewhat individual. Aneshensel et al (1995) and Nolan et al (2003) concur but highlight that while variation in experience occurs, so too does similarity. This is the particular contribution of these types of theories, which demonstrate the similarities that can occur in relation to the experience of informal dementia care.

3.6 In summary

This chapter presented a critical perspective on informal dementia care and demonstrated that the phenomenon is understood in terms of: related activities, impacts and consequences, burden, stress, appraisal and coping and as a dynamic temporally related process. Having considered the related literature, I now understand informal dementia care to be a multi-variate social construct that is inclusive of informal carer experiences and actions directed toward numerous dimensions of the overall phenomenon. However, in spite of the wealth of related research, the essence of informal dementia care still lacks in-depth understanding and we remain challenged to learn how best to support those who assist others (Butcher, Holkup and Buckwalter, 2001; Jansson, Nordberg and Grafstrom, 2001; Caron and Bowers, 2003; Chappell and Parmenter, 2005).

According to O'Connor, Phinney and Hulko (2009), a critique of much of the research exploring the experiences of persons with dementia is that it has not contextualised a person's experiences in terms of the socio-cultural context. It is my contention that the same can be said of much of the informal carer literature also. At its heart, informal dementia care is clearly relational (Ward-Griffin et al, 2007). Despite this, much of the research through which the phenomenon is understood emphasises the intra-psychic experience and the associated costs and consequences or is directed inwards to the relationship and process between the informal carer and care recipient.

However, Funk and Stajdhur (2009) suggest that the negative components of care, and I would add the positives also, are not only private but are related to considerations such as the macro-context of service availability and accessibility. In addition, the contexts within which the experience of dementia is encountered and negotiated are also influential, including interactions with other people, organisations and society. This suggests a need for research that might enhance the total experience of caring (Davies and Nolan, 2008; Ryan et al, 2008). In consequence, Montgomery and Williams (2001: S23) call for a wider research agenda that explores "the interface between the family and other social institutions", while others advocate for a broadening of informal caring-related conceptualisations (Caron and Bowers, 2003; Keady and Braudy Harris, 2009). To this end, a theory-generating approach grounded in informal carers' experiences is required to uncover new understanding with practical and theoretical inferences (Bowers, 1987). It was with this intent that the current study was conducted. Therefore, in the next chapter the methodological, epistemological and ontological issues that pertain to the construction of the CGT theory of 'Sustaining Place' (Chapters 6-9) will be considered.

Chapter 4 On Being, Knowing and Doing

4.1 Introduction

As grounded theory is a means of elucidating social complexity, it was considered suitable for the study of the experience of informal dementia care, which is socially-related and complex in nature. This chapter presents an overview of the methodological, epistemological and ontological concerns relevant to the conduct of this CGT study. According to Creswell et al (2007), the researcher should begin a research inquiry by making explicit their position in relation to such matters. However, my epistemological and ontological stances were formulated as the research progressed. This is because consistent with the CGT approach to the substantive field; I did not pre-specify related theoretical perspectives. Nursing continues to grapple with the complex and opposing tenets of the scientific method (using the practices of the natural sciences) and the need to study the social world as a distinct entity requiring other modes of study (Hammersley and Atkinson, 1995). Grounded theory is "not exempt from this tendency to multiple modes" (Annells, 1997b: 176). Situating this study in terms of its philosophical and grounded theory basis was consequently challenging, due to the number and contradictory nature of the available possibilities. However, resolving my orientation to these matters enabled me to clarify and explain my ontological and epistemological positioning and the means by which I accessed knowledge of the substantive field (methodology). This chapter presents my stance in relation to these matters.[25]

4.2 Philosophical positioning – epistemology and ontology

In nursing, the term paradigm has traditionally referred to quantitative and qualitative paradigms. Qualitative research is suggested to elucidate "life-worlds "from the inside out" and by doing so it seeks to contribute to a better understanding of social realities and to draw attention to processes, meaning patterns and structural features" (Flick, Von Kardorff and Steinke, 2004: 3). This study fits within this description, as its focus is on informal carers as social actors and the processes they engage in within their social realities. However, the qualitative/quantitative distinction belies the heterogeneity of the terms and linked debates (Clark, 1998; Morrow, 2007). This is because it is not possible to categorise theoretical perspectives, methodologies and so on in such a simplistic way (Lincoln and Denzin, 2005;

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[25] Issues relating to data collection, analysis and form of data presentation are referred to as the methods of the research and will be explained in relation to this study, primarily in Chapter 5.

Carter and Little, 2007). Neither is it possible to situate 'grounded theory' research in a singular manner. This is because diversification across forms of inquiry has resulted in numerous perspectives and practices. Similarly, presenting paradigms, approaches and lists of associated methods can contribute to an inaccurately simplified view (Denzin and Lincoln, 2005). Instead, paradigms are better understood as lenses or frames, which act as mechanisms to provide disciplinary knowledge (Weaver and Olson, 2006). They contain the researcher's ontological, epistemological, methodological and axiological[26] assumptions (Morrow, 2007). From this perspective, a paradigm functions as a milieu structuring the nature and content of the reality to be considered. Debates surrounding such considerations relate to some degree to a struggle for legitimation. However, Lincoln and Guba (2003) suggest paradigms are starting to interbreed, in that those previously incompatible may, using an alternative conceptual lens, inform each others' perspectives. As such, it was important for me to comprehend the similarities and differences within and between standpoints. This was also central because CGT is not restricted to a particular lens, as it can employ various epistemological perspectives depending on the data and the ontological perspective of the researcher (Holton, 2007).

4.2.1 On knowing - epistemology

According to Carter and Little (2007), it is not possible to engage in knowledge creation without at least a tacit assumption relating to what knowledge is and how it is constructed. In the main, two epistemologies are commonly linked to the conduct of grounded theory research – objectivism and constructionism.

4.2.1.1 Objectivism

Objectivism refers to a particular epistemological view that things exist (and meaning inheres within them) objectively and independent of individual consciousness and experience. It is possible to know the world as it is, in a value neutral sense, because research separates the knower from the object of knowing (Gillett, 2004; Johnson and Onwuegbuzie, 2004). The epistemological perspectives aligned with objectivism are: empiricism, positivism and post-positivism. Positivist philosophy, and its precursor empiricism, have their roots in the Enlightenment period (Smith, 1998), whose project was to search for ultimate truth using rationality and human reason. This contrasted with the preceding medieval emphasis on the church as the only source of truth. Positivism concerns itself with exploring the interconnectivity of phenomena through experience and observation. This equates to a realist

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[26] Issues relating to axiology and my ethical comportment in this study will be considered in the following chapter (Chapter 5, Section 5.9).

ontology in which there is a knowable correspondence theory of truth equating to external reality (Hammersley and Atkinson, 1995; Clark, 1998). The scientific method is used to establish factual truth via observation, experimentation and comparison (Crotty, 1998). According to Henwood and Pidgeon (1993: 15), quantification is historically the "sine qua non" of the scientific method, emphasising universal laws that can describe, explain and predict habitual relationships among variables. Positivism uses empirical theory and approaches that generally employ large data sets, measurement, statistical analysis and prediction and control. Studying the social world in this manner suggests that knowledge is discovered that can be used to control and regulate society through immutable all embracing principles (Smith, 1998; Burr, 2003). Positivism reached its peak in the 1930's and 1940's with the logical positivists, for whom the verification (or falsification) of hypotheses was the means to establish truth.

However, the conviction that it is possible to identify representations of the world as true or false has been contested (Gillett, 2004). Crotty (1998) suggests the issue is not with what positivist science does, it is with the status afforded to the resultant knowledge. It is generally accepted that positivism, as originally conceived, is un-supportable. Researchers now more commonly subscribe to the canons of post-positivism, which questions the absolute objectivity, predictive capability and pre-eminent view of the traditional positivist approach. Post-positivists accept the existence of an external reality but are less certain about the ability to fully apprehend the world (Clark, 1998). Objectivity is an ideal and researchers occupy a less absolutely objectified distance from that which is to be known. They consequently endeavour to approximate truth and not capture its entirety (Benton and Craib, 2001). While prediction and control are still aimed for, ontologically it is accepted that the social and natural worlds are different and imperfectly knowable (Annells, 1996). This corresponds to a less naïve perspective on reality. Post-positivist research involves multiple investigations and the acquisition of knowledge through convergent findings (Haverkamp and Young, 2007). Researcher involvement and influence are conceptualised as integral to the human enquiry process and findings are contextually bound. Truth therefore cannot be universally generalisable. Post-positivism has a well regarded provenance and continues to be extensively used in experimental and survey research in the nursing, health and social care arenas.

However, it is suggested that objectivism is not sufficiently sensitive to the varied contexts of the "social world in which all of us … live our lives" (Sabat, 2001: 94). For example, use of stress or burden measurement scales, to explore discrete aspects informal dementia care (Chapter 3, Section 3.5.3), while facilitating data comparability are simultaneously a-contextualised and socially mute. Additional perspectives are consequently needed to underpin research of such social phenomena, which require study in their natural state (Atkinson and

Hammersley, 1994). Researchers who agree perceive social phenomena as uniquely distinct from physical phenomena because people's actions are influenced by inherent social meanings that are constructed and reconstructed. As such, social phenomena cannot be reduced to linear causal relationships, generalisable truth and predictive laws. Therefore, for the current study, it was decided that objectivisim would be epistemologically unsuitable despite its important contribution to the informal carer research field in dementia. This was because objectivism is inconsistent with in-depth understanding of interaction in the social fabric of daily life (Sabat, 2001). Hence, constructionism emerged as salient to the particular concerns of this study.

4.2.1.2 Constructionsim

"Homo sapiens is always, and in the same measure, homo socious" (Berger and Luckmann, 1966: 60).

This study relates to knowledge of the social reality of informal carers of persons with dementia. The research is underpinned by the belief that the social world differs from the natural world and that in consequence, knowledge of this world will be intrinsically different (Shotter, 1989; Outhwaite, 1998; Lierbucks, 2001). I concur with Schutz (1972), who perceives this world as the objects and happenings in the socio-cultural context of commonsense thinking of people living in relations of inter-connection to others. In the conduct of related research, working hypotheses are generated and concepts are constructed from data. Constructionism is rich, complex and incorporates an emic idiographic approach to inquiry (Schwandt, 2003). According to Crotty (1998), constructionism in one guise or another is the form of epistemology referred to in the majority of viewpoints other than those of positivism and post-positivism. Here, truth is not an objective externalised entity that can be directly uncovered or approximated (Clarke, 2005; Snyder, 2006). Instead, meaningful reality "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: 42). No construction is the one true interpretation. Instead, what counts is that the knowledge produced has pragmatic value (Crotty, 1998; Gergen, 2001). Similar to Glaser and Strauss's (1967) CGT, meaning is constructed through intentionality and active engagement with the world (Bryant and Charmaz, 2007). Constructionism is then neither ostensibly subjective (consistent with a postmodernist stance[27]) nor objective. Instead, constructionsim brings the subjective and objective together (Crotty, 1998).

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[27] Postmodernism opposes the possibility of unitary truth (as truth is relatively related to the localised standpoint of the viewing subject) (Parton, 2003). It advocates scepticism towards grand narratives and in doing so advocates self-reflexivity, a pluralistic outlook and relativist ontology (Lyotard, 1984; Butler, 2002).

In contrast to social constructionism, constructivism holds that people construct the world and meaning individually, implying the world is different for us all (Appleton and King, 1997; Burr, 2003). Constructivism is a cognitive meaning-making perspective that differs from social constructionism, where the collective social, inter-subjective, cultural, historical and political influences on meaning-making are emphasised (Crotty, 1998; Gergen, 2009). Importantly, the current study draws on social constructionism and not constructivism, which would limit the construction of dementia experience by informal carers to an individual activity. This would belie the social, cultural and other factors that influence the construction of meaning and actions relating to issues of concern to informal carers in this study. A reading of the seminal writers in the field suggests that social constructionism is in transformation. It has "left the gritty, exciting and perhaps even dangerous downtown streets of academia and has settled comfortably into its suburbs. These suburbs contain many diverse but largely non-threatening neighbours ..." (Stam, 2001: 291). Social constructionism is then best conceptualised as a mosaic (Gubrium and Holstein, 2008) of distinct and sometimes disagreeing ideas. These generally concur that social processes and language are critical to everyday life experience (Hackely, 1998; Burningham and Cooper, 1999; Nightingale and Cromby, 1999). The focus of enquiry is the social practices of people, their interactions and meaning-making, with different perspectives emphasising different dimensions of the social processes that produce and sustain realities (Holstein and Gubrium, 2007).

A number of recurring features broadly unite the social constructionist family. Firstly, a critical stance toward the taken for granted because, as Burr (2003) suggests, we must be critical of the assumption that our perceptions of the world simply surrender its nature. According to Nightingale and Cromby (1999), this led to two strands: one that promotes relativism and one that suggests social constructions, while relative emerge via social processes that are influenced by materiality and power. Secondly, understanding of the world is socially and culturally explicit and time and context bound. We are born into a cultural world of pre-existent symbols, which, according to Geertz (1973) and Harding and Palfrey (1997), we inhabit and are inhabited by. The social milieu provides us with these symbols that function as frames by which people interpret meaning. As we communicate, we construct the world (Gergen, 2009). A particular understanding is an artefact of the conditions that prevail and as such is no nearer the truth than other ways of knowing (Burr, 2003). Thirdly, is the dominance of social processes, which lead to the inter-subjective construction of knowledge through social life, particularly through language. Lastly, knowledge and action are intertwined. Constructed understandings encourage certain patterns of social action and exclude others, as they provide the boundaries for what people can do and how people may behave towards others (Burr, 2003). This has particular relevance when one considers the highlighted impacts of the socially constructed nature of dementia and informal carer discourses reviewed in chapters 2 and 3.

In terms of research, social constructionism exists in two major forms. Firstly, a form which focuses on micro structures of language use in interaction and secondly, a form concerned with the macro linguistic and social structures that surround social and psychological life (Burr, 2003). In micro social constructionism, multiple equal realities are possible. In contrast, macro social constructionism recognises the constructive power of language, in part related to material and social structures, social relations and institutionalised practices. Power is central to this form, which is influenced by Foucault (1972, 1976, 1979). I agree with Burr (2003), that these variants are not mutually exclusive, as both the context of constructed meanings and the structures and practices from which they arise require consideration. Regardless of type, social constructionism emphasises the discursive turn as critical (Nightingale and Cromby, 1999; Willig, 1999). In micro constructionism, discourse refers to the micro processes evident in language use. This referred to by Burr (2003: 63) as "an instance of situated language use", for example conversation or written text. While this is relevant to the way in which informal carers of persons with dementia construct meaning, my use of discourse also relates to its macro perspective. Discourse here refers to a historically influenced set of interconnected supporting statements, representations or meanings illustrating a subject matter or events in a certain way (Foucault, 1972; Butler, 2002). Thus, understanding of dementia is arbitrated through language. For example, the medical model of dementia emphasises pathological processes. However, alternative views conceptualise dementia experience as sociological and/or psychological in nature (Chapter 2).

As previously indicated (Chapter 2, Section 2.3), discourses in general (and here those relating to dementia and informal dementia care particularly) express the political authority of their users (Butler, 2002).[28] From this perspective, social constructionism explores language and action, not only what one says or thinks but the possibilities for engaging in action or being acted upon (Burr, 2003). As Gergen (2009) advises, one must firstly listen to the content of what is expressed and secondly to the implications for ensuing action. Social constructionism therefore challenges positivist reductionism (Willig, 1999) and its critical focus can stimulate consciousness raising (Burr, 2003). Language and knowledge, as socially constructed, are consequently not a direct unmediated correspondence to objectively knowable reality (Rorty, 1979; Nightingale and Cromby, 2002; Gergen, 2009). Epistemologically the link between words (signifier) and world (signified) is somewhat random, as language has a productive rather than

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[28] A similar perspective is inherent in Foucault's (1972, 1976, 1979) work on discourse.

reflective function (de Saussure, 1974; Edley, 2001). This contrasts with objectivism where language is understood to be a direct reflection of the things words refer to (Smith, 1998). In social constructionism, knowledge is consequently a constructed version of a phenomenon, deemed by society to have a certain truth value and is subject to change (Potter and Wetherell, 1987; Burr, 2003). This was demonstrated in chapters 2 and 3 where dementia and informal carer discourses were shown to have been variously constructed over time.

However, there are a number of important critiques levelled at social constructionism. Firstly, Willig (2001) and Burr (2003) refer to the death of the subject and/or absence of the self. Burr (2003) suggests that the extent to which, individually or collectively, it is possible to reconstruct self and/or society is not adequately explained. To address this, Parker (1999) advocates building agency and subjectivity back into social constructionism without perceiving them as simply residing within the person. Burr (2003), turns to Berger and Luckmann's (1966) 'The Social Construction of Reality' in order to reconcile the subject/society relationship. Herein, the relationship between person and society is dyadic. People construct the social world, although not freely, which then is taken as a form of objective reality to be responded to. This process is suggested to involve: externalisation, objectification and internalisation.[29] Thinking in this way, the person is an agent constructing the social world and yet bounded by it (Burr, 2003). Discourse is then a product of both the individual (micro) and social (macro) structures. Burr (2003) stresses the inter-relatedness of people, such that conduct is located in the interpersonal realm. Her perspective is influenced by the work of the symbolic interactionists, including Herbert Blumer (1969). Secondly, Nightingale and Cromby (1999, 2002) identify disagreements relating to extra-discursive influences on discursive experiences and the limits of social constructionism. In particular they cite embodiment, materiality and power as influential examples. In contrast to a limited analysis of the outcomes of related processes, their version of social constructionism calls for an account of how these 'real' factors contribute to social constructions. This is to enable the elaboration of the social, material and biological processes that mould subjectivities (Nightingale and Cromby, 2002).

In summary, the form of social constructionism advocated in this thesis incorporates a relational dyadic perspective that resituates the subject. The emphasis is on movement away from essentialism to the adoption of a questioning stance towards the social world. This is because objective approaches would be insufficient to the study of those for whom so many facets of life

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[29] Externalisation refers to attaching meaning to objects turning them into signs or symbols. In objectification, objects can be used by others as signs with externalised meaning. Internalisation refers to the socialisation that occurs through acquired meanings, passed on yet experienced, as if the world is pre-given and fixed (Berger and Luckmann, 1966).

are touched by dementia. Parton's (2003) position, similar to mine, is that real world issues are messy, indeterminate and not tightly formed. He suggests that social constructionism because of its acceptance of the fluidity of knowledge may have much to offer professional practice. For example, in terms of this study, drawing on social constructionism enables exploration of how dementia-related meanings are formed and then reflected on to and into the person. As such, a focus on language alone is held to be insufficient because there is a need to consider the impact and influence of the extra-discursive world on meaning-making and action (Nicolson and McLaughlin, 1987).

4.2.2 On being – ontology: from realism to relativism and somewhat back again

Some writers consider that social constructionism should confine itself to an epistemological concern; Gergen (2001: 425) expresses his "desire to see constructionism remain ontologically mute". However, in relation to the conduct of research, researchers need to make clear their position in relation to ontological matters. In this study, ontological concerns relate to the nature of the social reality of caring for a person with dementia. In essence, this issue is polarised between realism and relativism. This debate is important, as it affects researcher comportment towards the research phenomenon, participants, data and claims to legitimacy. In realism, the world has an ordered existence independent of the individual's perception of it, with observable regularities that serve as explanations (Williams and May, 1996; Norton, 1999). What is experienced as the social world exists but the researcher is an objective knower. Hence, realism is frequently aligned with objectivist epistemology. It was shown in section 4.2.1.1 that positivism was traditionally linked with naïve realist ontology but that post-positivists advocate a less naïve ontological perspective. This is because according to Dickens (1996: 71), "even those within its ranks recognise ... that no knowledge has fallen out of the sky with a label attached pronouncing "absolute truth"". In contrast, social constructionism is frequently linked with a relativist ontological position (Burr, 2003; Parton, 2003). As used here, relativism does not deny the possibility of a material world. Rather, it is the ability to know such a world that is questioned. Relativism conceives the possibility of multiple co-constructed and equally valid realities (Haverkamp and Young, 2007; Morrow, 2007). The form of knowledge that emerges is transactional and subjective, amenable to multiple formulations and influenced by historical, temporal and cultural factors (Guba and Lincoln, 1994). Truth is decentred and localised (Parton, 2003). The researcher relates to the social world and research phenomenon in an involved and connected manner (Atkinson and Hammersley, 1994; Hammersley and Atkinson, 1995).

Within the literature, relativism and realism are usually diametrically presented in terms of being incommensurably separate paradigms (Rolfe, 2006a). However, the more one reads the more one begins to question if this is the case. Indeed, Hammersley (1992: 50) suggests that there is danger in "backing ourselves into a corner" by deploying an obscuring dichotomy between realism and relativism. In a refreshing departure from many rhetorically presented descriptions of knowing and being, Crotty (1998) accepts that it is possible that a form of realist ontology can co-exist with a social constructionist epistemology. He suggests this is because social constructionism is at once realist (what is constructed is real) and relativist (it is historically and culturally situated and produced in a given social milieu). Nightingale and Cromby (1999: 9) similarly assert that the socially constructed nature of the world does not force alignment with "an unbridled relativism". This is because social constructions surround us but as they are socially constructed, this does not make them any less real (Lierbucks, 2001). This then leads one to question what form of ontology might enable a researcher to reconcile these seemingly opposed positions. How can one be simultaneously both realist and relativist and by doing so, how can claims to legitimate knowledge be made? Hammersley (1992) suggests that neither naïve realism nor naïve relativism will suffice. On the one hand naïve realism is problematic in its assertion that there is an objective relationship between knower and known. However, naïve relativism, because it assumes multiple realities, is subject to the critique that it renders social research pointless because all perspectives have equal claim.

A third perspective, referred to as subtle realism is presented as a means to address the impossibility of having certain knowledge claims of that we are a part of (Hammersley, 1992). Subtle realism suggests that a phenomenon can exist outside the researcher's knowledge of it and knowledge can be more or less accurate (Murphy et al, 1998). The aim is to represent reality from a number of perspectives, treated as equally true, and not to reproduce reality (Hammersley, 1992). The researcher can thus investigate independent knowable phenomena, constructing knowledge about which he/she can be reasonably certain. A shared ontology is inferred with the possibility of non-competing representations with slight epistemological differences (Heath and Cowley, 2004). Subtle realism occupies a middle ground between realism and relativism, which according to Murphy et al (1998) prevents having to choose paradigmatic polarity. It is consistent with the manner in which grounded theory is advocated by many contemporary writers on the subject (Bryant and Charmaz, 2007). What is suggested herein then, consistent with Nightingale and Cromby (2002), is the influence of a material world/reality beyond and before discourse to which language (albeit imperfectly) refers. Social constructionism is then both a material and linguistic practice that incorporates: discourse, agency, materiality and social constraints that limit the possibility of constructions (Burkitt, 1999; Burr, 2003). It is this subtle realist ontological position that underpinned the conduct of this study.

4.3 Methodological positioning

The CGT approach of Glaser and Strauss (1967) and Glaser (1978, 1992, 1998, 2001, 2003, 2005) informed this study. This is important because 'grounded theory' is a term used in the literature to describe variant research approaches. CGT offers a means to understand people's concerns, in this case informal carers' concerns, and how these are actively managed (Mc Callin, 2003).

4.3.1 Explicating Classic Grounded Theory

CGT methodology is used to explain the patterns arising in social life and human interaction (Wilson, 1989a, 1989b; Bigus, Hadden and Glaser, 1994; Chen and Boore, 2009; Wasserman, Clair and Wilson, 2009). An underpinning sociological assumption of CGT is that social life is not random. It exists as collections of behavioural consistencies/regularities, which can remain hidden to those engaged in living them. CGT enables the naming of these latent patterns, which Glaser and Strauss (1967: 32) consider pivotal to portray "the reality of social interaction and its structural context". Consequently, theoretical explanation of a social phenomenon (here how informal carers of persons with dementia address the problem of 'Living on the fringes' (Chapter 1, Section 1.3)) may be discovered (Benoliel, 1996; Kennedy and Lingard, 2006). Glaser (1978) identified two types of resultant basic social processes: a basic social psychological process that occurs to people or a basic social structural process relating to change in social structural formats. As such, grounded theory, while discovered from data is at once abstract of it and conceptually modifiable in the light of new data (Glaser, 2003). CGT is a primarily inductive methodology based on a concept indicator model and inter-changeability of indices (Bryant and Charmaz, 2007). It emphasises the inductive discovery of ideas in data, which are then deductively tested through ongoing theoretical sampling. A CGT consists of a set of conceptual categories and their hypothesised relationships derived from the systematic and constant comparison of incidents that expose the patterns, which explain how people solve their main concerns (Glaser, 1992, 1998, 2001, 2003, 2005). The theory produced is multivariate, parsimonious and middle range (Glaser, 1978, 1998, 1999).

The CGT researcher searches for the core category, which explains the majority of the variation in the data and serves as the integrating core to which the other categories are related. Use of this methodology can result in the conceptualisation of either substantive (relating to a particular/focused empirical area of enquiry) or formal theory (relating to a more conceptual area of enquiry). For example, the theory conceptualised in this study is a substantive theory faithful to the empirical situation of informal carers of persons with dementia. Data (evidence) are used to generate the conceptual categories and their properties and the evidence from which a category emerged is used to demonstrate the concept (Glaser and Strauss, 1967). Properties of categories are elucidated by comparing similar and divergent empirical indicators within the data. They broaden the emergent theory, enhancing its explanatory power. The means to produce a CGT are through an active and systematic engagement with the tools of the methodology. These are: simultaneous data collection and constant comparative analysis, theoretical sampling, theoretical sensitivity, memoing, sorting and writing.[30] The methodology also has four inbuilt quality criteria which it should satisfy – fit, work, relevance and modifiability (Glaser, 1978, 1998, 2003).[31]

4.3.2 Why grounded theory?

Research relating to stigma in dementia, which is where this study began, has not sufficiently accounted for experiences of social relations and professional terms such as stigmatisation are often used with little analysis of the social processes involved (Prior et al, 2003; Grytten and Maseide, 2005). Therefore, research that examines social phenomena and is grounded in the experiences of those whose lives are affected by dementia, including informal carers, is consequently required. According to Glaser and Strauss (1967) and Strauss and Corbin (1990, 1998), CGT is particularly suited to areas about which little is known or when a new perspective is required on a common phenomenon. CGT consequently offers an exciting means to approach informal carers' experiences with a fresh mind, in contrast to the commonly presented stigma-imbued or stress-burden oriented frames. Benoliel (1996) and Keddy, Sims and Stern (1996) suggest that nurse researchers have mainly tended to focus on the microcosm of nursing related issues to the neglect of the context of the social and political worlds. This was a concern when selecting a methodology to underpin the current study. CGT is appropriate where the "research question involves social interactions or experiences" and the intent is "not to test or verify existing theory" (Kennedy and Lingard, 2006: 103). This approach is widely used in health and social sciences research to identify issues of importance to people, create meaning and build theory (Mills, Bonner and Francis, 2006a). According to Charmaz (2005), grounded theory is also a suitable method to study areas that could relate to social justice issues. As the beginning focus of this enquiry related to stigma in dementia, grounded theory was an appropriate fit in

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[30] The components/methods of CGT will be elucidated in chapter 5, where they will be contextualised in terms of their use in this study.

[31] The application of these criteria in this study will be addressed in Chapter 11.

this regard. This is because the findings of the exploratory study (Nolan et al, 2006) suggested that social and structural discrimination and disruptions to social interactions were experienced by informal carers. CGT additionally provides a useful heuristic to the study of informal dementia care experience, as it has underpinned understanding of the experience of a number of chronic illnesses (Charmaz, 1991, 1994, 2006).

In addition, grounded theory contends that multiple theories are required to build more inclusive formal theories (Glaser and Strauss, 1967). Therefore, while there is extensive research exploring informal dementia care, some of which was explored in chapter 3, this does not foreclose the need for ongoing research. The grounded theory researcher's enterprise is to include existing theories in the constant comparative analytic process. Theory constructed by means of CGT can enable professionals and policy makers to better understand informal carers' experiences. The resultant knowledge can be used to address informal carer identified concerns. In this way, CGT is seductive. It promises relevancy and an opportunity to understand the experiences of informal carers of persons with dementia and to improve the provision, nature and form of caring and supportive interventions available to those whom they should benefit. Cognisant of the need to address people's concerns, Dewey (1954) also called for research that prevents an eclipse of the public, in this case the concerns and actions of informal carers. In using CGT, I was enabled to reside in close proximity to the worlds of informal carers and consequently to develop theoretical concepts, which both synthesised and transcended the empirical level data, demonstrating process associations. This is because using CGT enables the analysis of the "relationships between human agency and the social structures that surround us posing theoretical and practical concerns" (Charmaz, 2005: 508).

4.3.3 Grappling with forms – the remodelling debates

According to Boychuk Duchscher and Morgan (2004), clarification of the thinking that surrounds grounded theory is not straightforward. Grounded theory is suggested, by Woods (2003: 4), as being in a state of evolutionary flux, often "misconceived, misrepresented or misused". Informal carers of persons with dementia perceive their experiences and the associated meanings and actions as their reality. However, it is the very nature of reality that has fostered a vigorous debate in grounded theory and its proposed forms. Researchers consequently need to acquaint themselves with the polemics surrounding the remodelling of grounded theory and the implications for their research enquiries. Annells (1997a, 1997b) suggests that qualitative research approaches are situated in a historical context and are subject to development. According to Miller and Fredericks (1999), data may be subject to multiple interpretations and it may be possible to produce other models of grounded theory with different contexts of discovery to that of Glaser and Strauss (1967). Certainly, an exploration of the literature exposes a number of suggested positions, including: CGT (Glaser and Strauss, 1967; Glaser, 1978, 1998); Strauss and Corbin's (1990, 1998) version; constructivist/constructionist grounded theory advocated by Charmaz (1994, 2005, 2006), Mills, Bonner and Francis (2006a, 2006b) and Mills et al (2007); situational analysis (Clarke, 2005) and Denzin's (2007) listing of seven versions. However, a review of this literature indicates a lack of consistency in relation to where different writers situate both CGT and the proposed remodelled formulations.

Annells (1997a, 1997b) contextualises grounded theory in the context of the eight moments proposed by Denzin and Lincoln (2005), relating CGT to the modernist phase. Mills, Bonner and Francis (2006a) and Annells (1996) noted that CGT was post-positivist in orientation, moving towards constructivism. Charmaz (2003) relates Glaser's (1978, 1998) CGT to positivisim, as she sees it as inherently objectivist and Strauss and Corbin's (1990, 1998) version as post-positivist. Keddy, Sims and Stern (1996) suggest that much of the critique of the CGT version relates to the language employed, which was positivistic reflecting the time it was written. However, Glaser (2001) writes that CGT is transcendent and abstract of the need to accurately describe. It is consequently devoid of imperatives to present findings, prove/disprove a hypothesis or to reproduce the voice of participants. Recently proposed versions emphasise a subjective dialectic epistemology. For example, Charmaz (2003, 2006) advocates constructivist grounded theory with a relativist stance on social reality. Glaser (2003) discusses at length these 'newer modes'. To him, remodelling results in a mix of grounded theory and qualitative data analysis that results in conceptual description. He attributes this term to Strauss and Corbin's (1990) version, stating it forces data by using preconceived lenses. Remodels have also been critiqued by others, with some criticising Strauss and Corbin's (1990, 1998) as formulaic. For example: Robrecht (1995) suggests the approach makes emergence problematic, Keddy, Sims and Stern (1996) infer an enforced rigidity, while Melia (1996: 376) suggests "the technical tail is beginning to wag the theoretical dog". Reviewing the positioning of the remodelled stances can be bewildering with claim and counterclaim appearing to be cogently presented.

Glaser (2001, 2003, 2005) however insists that only CGT can be termed grounded theory and that it is "not the hand maiden ... of a particular discipline and/or any one theoretical perspective" (Glaser, 2005: 127). He portrays remodelling as unfortunate because this lowers the level of the general methodology. CGT is not linked with a particular ontological or epistemological position and using an incorrectly pre-determined lens is a critique of grounded theory research (Becker, 1993). According to Glaser (2005) and Holton (2007), arguing which theoretical perspective grounded theory is linked with is moot because it is a general method beyond such arguments. Instead, Glaser (2005) advocates openness to a multitude of perspectives, rather than beginning from a particular perspective which forces the data and results in a narrow view. In-depth understanding of Dr Glaser's work through dialoguing with him and his writing, reveals that it is however possible to adhere to the CGT methodology, while justifying a particular ontological and epistemological stance. The difference is that the stance adopted is one that has theoretically sensitised the researcher and earned its relevance to the substantive theory. Thus, Glaser (1998, 2003) advocates a delaying of philosophical wrestle (as was the case in this study) until a grounded theory product is emergent. This facilitates heterogeneity and the examination and clarification of position as the study proceeds.

Glaser (1998) relates the crux of debates over epistemological forms to claims in relation to which form of knowledge addresses issues of data accuracy most successfully. However, he asserts that what does matter is how well the product of a CGT study corresponds to the world from which the data was gathered and that it provides conceptual understanding (Glaser, 2003). As earlier stated, this prevents drift to professional rather than participant concerns, which "tap the natural organisation of the data" (Glaser, 2003: 87). Therefore, it is not claimed that CGT is above or superior to other approaches: it is simply different and designed to fulfil a particular purpose (Glaser, 1998, 2001; Christiansen, 2007; Holton, 2007). It can be used with any data (quantitative or qualitative) or data combination, despite many writers referring to its use only in terms of qualitative data.

4.3.4 Clarifying my approach

Consistent with Glaser (2001, 2003, 2005), my stance is that there is one form of grounded theory - CGT - that can, with earned relevance, be linked to particular ontological and epistemological positions through a researcher's theoretical sensitivity. The CGT methodology is simply that - the methodology. Adopting a prior frame of reference, or particular theoretical or paradigmatic perspective, in advance of the study would preconceive relevance. Instead, in this study, the use of CGT enabled the conceptualisation of the social reality of informal carers', while enabling my familiarisation with exciting approaches from which I could potentially draw on. According to Morrow (2007), such a researcher can traverse paradigms knowledgeably in response to both the research question(s) and the emergent data. This is consistent with the CGT call to look to the nature of the data as "everything begins with the data" (Wasserman, Clair and Wilson, 2009: 358). It is also highly consistent with nursing, which accepts multiple ways of knowing (Tarlier, 2005). The power of CGT is its lack of impeding influences on researcher autonomy. Thus, from the perspective of Glaser (2005), in this study I wanted to become a curious transcender! This is not to assume that the researcher is a tabula rasa. I had previous experience of caring for persons with dementia and conducting research in the field of dementia.

In the initial stages of the study, I experienced anxiety that this would lend my inquiry a particular experiential tint (Laudan, 1977). However, I recognised that I was simultaneously limited due to my restricted knowledge of a wide range of philosophical and theoretical perspectives.

Through engagement with a range of literature, and by considering how the positions encountered might/might not relate to the discovery process, I developed a personal understanding of the available philosophical and methodological stances. Side by side engagement in clarifying my philosophical stance, alongside engagement in the research process ensured that my theoretical sensitivity was expanding as my competence in using CGT was growing. A researcher's worldview comes from the nature of the data and engagement in a clarification process. This is the case particularly for the novice researcher who may be naïve as to the ins and outs of such debates and learns as they go. This is referred to by Freshwater (2000: 29), as learning "about the process of researching through learning in the process of carrying out the research". As my understanding of the available positions grew, the structures and shared understandings with which the informal carer interact emerged as influential in terms of participant experiences, constructed meanings and ensuing actions. It became clear that sole reliance on symbolic interactionism, which locates the seat of interpretation within the person, was clearly insufficient. Glaser (2005) agrees and states that this approach could blind a researcher to other relevant perspectives because there are always social structural, social organisations, systems, cultural and economic features at play. In consequence, I recognised the need to consider both the subjective participant experiences and those of a more collective nature, in terms of the structures within which informal carers' experiences are located. Using CGT, as intended by Glaser (1978, 1992, 1998, 2001, 2003, 2005), enabled me to do this.

I recognised that my life and participants' lives were heavily immersed in social contexts that influenced both constructed meanings and potential for actions. This enabled me to apprehend that informal carers interpret and construct meaning through social interaction. Thus, the impetus for social constructionism and subtle realism evolved from my recognition of the importance of understanding that data provided by participants could take a number of forms, and was not always clear even to participants themselves. Glaser (1978) cautions the researcher to be aware of this. The importance of context and the social construction of the reality and nature of dementia became clearer. I understood that a-contextual concentration on participants' overt responses could, as Charmaz (2003: 257) writes, "lead to narrow research problems, limited data and trivial analyses". Social constructionism fit with my use of CGT because the intent of the theoretical outcome was to explain how informal carers address the issues of concern they face. As the conceptualised domains of action involved micro, meso and macro level interactions, with individuals, organisations and societal structures, I used the concepts of social constructionism to theoretically sensitise me to look for emergent processes in the data. As per Charmaz (1994), rather than it being the assumptions that underpin the theoretical perspective which informed my orientation, it was the questions and premises that flowed from it that were salient to the conceptualisation of the substantive grounded theory.

4.4 In summary

According to Crotty (1998), it is necessary that research is reported in a manner that illuminates the researcher's assumptions and the way in which a researcher engages with the research process. Rather than being faced with a choice of which label best suits us as researchers, Schwandt (2003: 320) suggests that what is more salient is the decisions we make when confronted with choices about how we wish "to live the life of a … researcher". To this end, this chapter explored the philosophical and methodological issues relevant to this thesis. Glaser (1998, 2005) does not, as many infer, reject the potential relevance of various epistemological and ontological positions to the discovery process. He fully supports the need to read and grasp such positions to increase theoretical sensitivity but to wait for relevance to become clear. This was the approach adopted herein. Not to have done so, would have demonstrated my naivety of the nature and intent of CGT. In relation to research methods, Fine (2007: 460) refers to expanding the methodological imagination to "the serpent eyes" of practice (on the ground)" and "eagle eyes" of theory (flying over). The linkage between these two aspects was a complicated journey but none the less a necessary one, particularly in light of the CGT controversy. In Chapter five, I will continue to illustrate how I lived my life as a researcher by describing the way in which CGT was used to conceptualise the substantive theory of 'Sustaining Place' presented in Chapters 6-9.

Chapter 5 On Process - How This Study Was Carried Out

5.1 Introduction

Carter and Little (2007) refer to methods as research action justified by a chosen methodology. This chapter consequently follows the last, by illustrating how I applied the methods of the CGT methodology in this study. The chapter begins by explaining the genesis of the initial research and how this evolved into the ongoing research purpose, aim and questions. Issues pertaining to participant sampling, access, data collection and ethical considerations are then described. Finally, the iterative process of constant comparative analysis that was used to conceptualise the basic social process of 'Sustaining Place' (Chapters 6-9) will be illustrated.

5.2 Genesis of the study

Having a diagnosis of dementia can imply that the person can be perceived as different. This creates the potential to be subjected to stigmatisation and discrimination by others (Joachim and Acorn, 2000). In society, those who are stigmatised may become marginalised and encounter difficulties in participating in many facets of social life. Importantly, stigma can also be experienced by informal carers, in which case it is referred to as: courtesy stigma, stigma by association or family stigma (Goffman, 1963; Mavundla, Toth and Mphelane, 2009; Werner, Goldstein and Buchbinder, 2010).[32] Informal carers, in common with the person with a stigma-linked condition, are consequently at risk of increased emotional effects, degradation and social isolation (Blum, 1991; MacRae, 1999; Angermeyer, Schulze and Dietrich, 2003; Green et al, 2005; Chang and Horrocks, 2006). Because of a dearth of Irish research on stigma in dementia, the Alzheimer Society of Ireland commissioned the initial six months of this study to explore this phenomenon and its effects. However, using the general principles of the CGT approach, it became clear that 'stigma' is a term most commonly used by professionals to name a professional concern. Following the publication of the exploratory funded report (Nolan et al, 2006), the study continued with the support of the Alzheimer Society of Ireland. Via a rigorous engagement with the components and processes of the CGT methodology, which included the collection of additional data, the theory of 'Sustaining Place' was conceptualised. As previously explained (Chapter 1, Section 1.3), the primary concern/problem of informal carers, in this study, was identified as 'Living on the fringes'. While this problem involved the components

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[32] This form of stigma will be addressed, in terms of this study, in Chapter 10 (Section 10.4).

and consequences of stigma, informal carers' principal concern was conceptualised as broader in nature than just 'stigma'. Therefore, consistent with CGT, which explores a substantive area and concentrates on what is then discovered, the ongoing conceptualisation process focused on this informal carer identified concern.

5.3 Study purpose

The purpose of this study was to produce knowledge with which to build a conceptual understanding of living with dementia from the perspective of informal carers, by discovering how they resolve their principal concerns.[33] The intent was to advance current understanding by developing a theoretical model based on the meanings that dementia experiences and linked actions hold for informal carers. A further purpose was to inform health and social care policy and practice by making recommendations to make a real difference to quality of life and health and social care for informal carers of persons with dementia. This is important because without an understanding of the issues that are of actual concern to informal carers, it is unlikely that interventions at policy, practice or societal levels will have a positive impact on their lives.

5.4 Study aim

The aim of the study was to develop a theory to explain the processes employed by informal carers of persons with dementia to resolve issues of primary concern to them.

5.5 Research questions

The fundamental research question was 'what is the nature of living with dementia from an informal carer perspective?' To address this question, and consistent with my use of the CGT approach, the following questions were formulated:

1. What is the principal concern/problem of informal carers' of persons with dementia?
2. What is happening in the data to account for the problem?
3. What are the processes that explain the actions that informal carers engage in to address the identified problem?

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[33] For the purposes of this study, an informal carer was defined as a person mutually identified by him/herself and gatekeepers from the Alzheimer Society of Ireland, as the primary carer for a person with dementia.

5.6 Theoretical sampling

Sampling was driven by the need to learn about informal carers' experiences. Initially, non-probability purposive sampling was used to locate and recruit participants with direct dementia caring experience. As concepts and categories emerged, purposeful sampling (beginning with the first participant reply) gave way to theoretical sampling. This "is the process of data collection for generating theory, whereby the analyst jointly collects, codes and analyses ... data and decides what data to collect next and where to find them in order to develop ... theory ..." (Glaser and Strauss, 1967: 45). As such, sampling is focussed by the analysis of previous data and the emergent theory (Holton, 2007; Neill, 2007). Theoretical sampling was used to ensure theoretical coverage and not descriptive or population coverage. Bigus, Hadden and Glaser (1994: 54) refer to this as "a parsimonious search for variation around emergent process characteristics". The sample size was determined by this aim and not pre-specified. Glaser and Strauss (1967) note that CGT is supportive, if not encouraging, of taking time out to work with the data before collecting more. This occurred here as interviews were completed between May 2006 and December 2008, working extensively with the data throughout this time. As the problem of 'Living on the fringes' and the consequent threats to place were identified, theoretical sampling became driven by the need to constitute emergent categories through the discovery and saturation of their properties.

The intent to densify the emergent theory and develop a deeper understanding of the emergent concepts led to theoretical sampling beyond informal carers.[34] According to Kennedy and Lingard (2006), this practice is common in grounded theory studies where insights from a range of perspectives contribute to fertile understanding of the phenomenon under study. To this end, I interviewed: a person with dementia, a number of allied health professionals working in the field of dementia and a disability organisation representative to add to the conceptualisation process. This enabled the checking out of my ideas from different perspectives. This data was used in two ways. Firstly, as the purpose of sampling in this study was to learn more about informal carers' experiences, I could explore in greater depth why certain experiences recounted by them, and their consequent actions, might be occurring. For example, I was able to better understand the impact of the ways in which dementia is socially constructed and experienced. Secondly, and unexpectedly, some of the allied health professionals (AHPDO2 and AHPDO6) also revealed that they were or had provided informal dementia care. Therefore, these participants provided a valuable dual perspective on the informal dementia care process.

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[34] The data was coded in the same way as that from informal carers. Extracts from this data will be presented, where appropriate, in support of the components of the theory (Chapters 6-9).

5.7 Gaining access to participants

5.7.1 Informal carers' of persons with dementia and the person with dementia

To access informal carers and the person with dementia, gatekeepers from the Alzheimer Society of Ireland approached potential participants who fulfilled the relevant study inclusion criteria (Appendix 1). They gave the potential participants a letter of invitation (Appendix 2) and study information sheet (Appendix 3). As such, gatekeepers acted as a liaison to protect the interests of potential participants by ensuring that they would not be exposed to inappropriate or excessive research demands (Mander, 1992). If an informal carer wished to discuss participation, they completed the bottom portion of the letter of invitation and returned it to me in the stamped addressed envelope provided. Potential participants were then contacted to discuss participation. In total, 20 interviews were conducted with 21 participants (20 informal carers (CFM1-CFM20) and one person with dementia (PWD1) across varied geographic areas within the Republic of Ireland. Informal carer participants represented a continuum from the earliest stage of dementia to having lost a loved one through dementia. A profile of this participant group is presented in Appendices 4 to 8.

5.7.2 Allied health professionals and disability organisation participants

Theoretical sampling of allied health professionals and a disability representative, who either had knowledge and/or experience of stigma and/or dementia, was carried out using specific inclusion criteria (Appendix 1). This ensured that participants with particular knowledge and expertise to enhance understanding of the substantive area and emergent concepts were accessed. In some instances, a representative of the Alzheimer Society of Ireland acted as the gatekeeper and in others an intermediary fulfilled the role. A letter of invitation and relevant study information sheet was forwarded to the identified persons. If a potential participant wished to discuss participation, they completed the bottom portion of the letter of invitation and returned it in the stamped addressed envelope provided. I then contacted the person to discuss participation. Where an individual was interviewed in their workplace, permission to access the site was obtained from the appropriate employers who were also supplied with study information. In total, nine interviews were conducted with various allied health professionals and one interview with a representative of a national disability organisation (AHPDO1-AHPDO10). A brief profile of this participant group is presented in Appendix 9.

5.8 Data collection

5.8.1 Foundational premises

The primary data collection instrument used in this study was an interview. Highly structured data collection methods are inconsistent with CGT. This is because the imposition of rigid structure would constrain exploration of the substantive area and inhibit participants from explaining their major concerns and how they are addressed. Consequently, I approached each interview as a negotiated social interaction on a potentially sensitive topic, conducted within a specific social milieu. An open, in-depth conversational approach was adopted. Many writers refer to this form of interview as a conversation with a purpose (Burgess, 1984) and researcher and participant as conversational partners (Rubin and Rubin, 1995). However, I was present in a particular capacity, as were participants, so the nature of our conversation could not be said to be naturalistic in an everyday sense. Similarly, Kvale (2006) refers to the fantasy of democratic relations within interviewing, while according to Mishler (1979, 1986), meaning is always conceptualised within a particular social context. As such, researcher and participant are struggling to take their personal, social and cultural positioning into account (Kvale, 1996; Kvale and Brinkman, 2009). Both actively construct meaning, assume what is real, occupy social statuses and roles, and possess knowledge stocks and purposes that influence views and actions in each others presence (Charmaz, 2006). It was these foundational premises that, consistent with social constructionism and CGT, underpinned the conduct and analysis of the interviews.

5.8.2 Pilot interviews

Before commencing data collection a pilot study was conducted consisting of three test interviews. This was to evaluate the suitability of my approach and refine the interview process by addressing potentially problematic areas (Mead, 1993). In contrast to traditional pilot interviews, the test interviews were facilitated by a professional psychotherapist. Using this approach, I could evaluate my own performance and I had the benefit of receiving critical feedback from a professional (clinician and researcher) interviewing on a daily basis. I considered this was more ethical than conducting test interviews with pilot participants and then potentially not including their contribution in the main study. The experience demonstrated my nervousness and tendency to want control. This contrasted with Hand's (2003: 20) advocating the construction of a "joint account". I also found that the level of cognitive and affective engagement required was greater than anticipated. It was clear that the reflexive demands of active thinking, active listening (to ascertain the process and substance of what was said) and the requirements to be sensitive to participants and data would be significant (Keats, 2000;

McCann and Clark, 2005). The pilot interview experiences consequently led to more realistic expectations during actual data collection. They also highlighted the need for minor adjustments to my overall approach (for example: body language and recording device placement) and augmented my confidence. In addition and with participants' permission, my principal supervisor listened to a number of the early interview recordings in the actual study and provided me with feedback, for example in relation to my questioning pace and technique. I used this feedback to inform the conduct of the following interviews.

5.8.3 The interviews – negotiated conversations with purpose

According to Mills, Bonner and Francis (2006a), the researcher engaged in CGT needs to plan for time spent with research participants. Consistent with Corbin and Morse's (2003) approach, I approached each interview in terms of four inter-related phases (see below), each involving cognitive, affective, social and ethical factors.

5.8.3.1 Pre-interview phase

The pre-interview phase began once I received a participant's reply slip and initially phoned him/her. Time was devoted to this preliminary contact because the opportunity to establish rapport was minimal. This phase extended to meeting to conduct the interview and involved a number of activities. These included: establishing my credentials, providing an overview of the interview process, research approach and the nature of participant involvement, and confirmation of each participant's consent to participate. In addition I sought each participant's consent to digitally record the interview, demonstrated how the recorder worked and we mutually agreed where it would be positioned so that it would cause minimal distraction. In this interview phase, a number of participants sought my credentials, commitment to the subject and knowledge of dementia. For example, participant CFM03 brought out articles on dementia and questioned me on some of the content. I quickly realised that I needed to earn the right to be entrusted with participants' experiences. This was important because for many participants, the opportunity to share their story had been minimal or non-existent. To demonstrate my authenticity, I explained my professional and research backgrounds and interest in and experience of dementia. I spent time finding out about each participant and I interpreted interactions such as: being shown around people homes or work places, being shown family photographs or a memory book, or being invited to have tea and meet family members or colleagues etc, as positive indications of participant comfort in my presence. This phase also involved obtaining some background information (Appendices 10 to 12), while acknowledging Glaser's (1978) caution against assuming the relevance of factors such as age, sex etc (what he terms face sheet data) to the analysis. In contrast, my purpose was: firstly, to establish who participants were and secondly, to enable ongoing theoretical sampling. The activities in this phase were crucial to the nature and quality of participants' subsequent engagement and the interview outcome. As much time as was necessary was consequently devoted to this period. This pre-interview phase generally ended when the digitally recorded component began.

5.8.3.2 Tentative and Immersion phases

As participants and I became increasingly engaged in the conversational moment, I experienced these phases as two levels of the one phase. This was despite Corbin and Morse (2003) describing them as distinct. Because I was anxious to avoid preconceiving or forcing the emergence of data, participants were invited to focus on issues of importance to them. Each interview began with a broad opening question, for example: "Can you tell me when you first noticed that something was not right?" Flexibility was then required as interviews were led by the nature of participants' responses. This created a social milieu that facilitated the exploration of issues of meaningful concern to participants without undue influence, constraint or direction from me. As I was conscious of the interview's potential intrusiveness, I sought a strategy to sensitively manage this. I found minimal interview guidance within the CGT texts, so I drew on the laddered questions approach developed by Price (2002, 2004) for his grounded theory research. To comprehend social process, Price (2002) designed the approach for studies which aim to discover how participants' thoughts, beliefs and actions relate to one another. The approach assisted me to align the study purpose with the tenets of data collection outlined by Glaser (1978, 1998). In laddered interviewing, a researcher operates from an ethical base, aiming to understanding participants' needs. By evaluating participants' responses, I could select from three levels of progressively deeper questions: 1) questions inviting descriptions of or about action, 2) knowledge questions and 3) personal philosophy questions (Price, 2002). It took time to become skilled in this approach because I was aware that the higher level questions were more intrusive. Learning to read participant responses, avoid mixed level questions and remain attuned to the data was demanding. To help, I used a sheet of paper to note issues that I identified and might wish to return to later in an interview. This enabled me to avoid interrupting a participant and to select a suitable time to ladder up (or down) the question level according to participants' responses. As I internalised the approach, I experienced increasing comfort and no longer consciously needed to think about my technique.

In CGT, the iterative nature of the interview process develops hand in hand with constant comparative analysis, memoing and theoretical sampling. These result in a progressively sharpened focus to interviews situated around the tentative emerging theory, whose categories are the subject of subsequent interviews (Wimpenny and Gass, 2000). Consistent with this orientation, I constructed/reconstructed interview topic guides (Appendix 13), which functioned as aide memoirs during interviews. These were used organically and not in a structured manner. This enabled exploration of emergent categories and related properties, while enabling participants' narratives to guide the ongoing enquiry process (Chiovitti and Piran, 2003). Sometimes informal carer participants became tired or had to stop to care for the person with dementia or professionals had limited time due to work demands. In consequence, interview time was precious and I was anxious I could miss my chance to access valuable data. However, I learned it was not the length of an interview but faithfulness to participants' concerns and the CGT approach that held the potential to enrich the emerging theory. I also realised that as a nurse, I was part of a shared culture with the allied health professional participants and because of this there could be a risk that I might simply accept and not sufficiently question their data. To guard against this, I adopted three strategies. Firstly, as described by Holloway and Wheeler (2002), I tried to act as a 'cultural stranger' by using probes to elicit elaboration and meaning (Appendix 13). Secondly, I theoretically sampled outside the areas in which I held a shared frame of reference. Thirdly, by allowing participants to elucidate their concerns, two of the professionals (AHPDO2 and AHPDO6) spoke about their personal experiences of caring for a close family member with dementia. Ward-Griffin (2008: 2) refers to those who engage in formal and informal caring as "double-duty caregivers". As previously explained, the inclusion of such participants in this study was unexpected but enriching because these persons elucidated the dual perspectives of informal and professional carer.

5.8.3.3 Emergence phase

To protect participant well-being and comfort, it was important that release from the interviews was not sudden and so time was allowed to engage in winding down. This represented a shift to a less intense emotional level (Corbin and Morse, 2003). It involved drawing the interview to a close (for example, by asking informal carers to identify means of improving their experiences) and the time following cessation of recording. To check my interpretation, I summarised what was discussed. Each participant was asked how they had experienced the interview and if they would have changed anything. This enabled me to: amend my approach if required, to check participant well-being and to assess the potential need for psychological or informational supports. All participants expressed their satisfaction at having participated. Some were anxious to be reassured that their contribution had been valuable and could assist others. Participants were also asked if there was something they wished to add or questions they would have liked asked that had not been. Often participants would engage in what I named 'talk off tape'. This could be general or about an issue of concern that either had not occurred earlier or that they did not wish to be digitally recorded. This data was subsequently analysed if a participant gave permission to do so. Field-notes were completed after each interview, referring to points of significance about interview contexts, content and processes. These were also used as a data source for analysis.

5.8.4 Positioning 'self' in relation to 'other'

To demonstrate respect for each participant, I needed to show reciprocity, reverence for every person's dignity and clarity in my positioning in relation to each as an individual. To help, I adopted the stance of a reflexive learner (Charmaz, 2006; Knapik, 2006) orientated towards mutual exploration and discovery of a world shared within the interview. Demonstration of respect for participants and their experiences requires building rapport and earning trust (Clarke, 2006; DiCicco-Bloom and Crabtree, 2006). However, Glaser (1978, 1998) indicates that as CGT data gathering proceeds, a scoop and run orientation can enable discovery and elucidation of the processes participants engage in. From my perspective, this would have jeopardised respect for participants. Dey (1999) and Charmaz (2006) agree and critique such actions as dispensing with reciprocity in favour of gaining data. Acting in such a way would prioritise the study over participants' well-being. In light of the sensitive nature of the substantive area, the effect a data focused approach could have on participants and their potential to share experiences that mattered to them was concerning. However, at all times the well-being of the individual participant was placed ahead of the collection of data. According to Mishler (1999), participants don't simply start to recount the intimate details of their lives. Instead, they build to their story as they increasingly trust a researcher. Consequently, prioritising participant well-being enabled participants to recount their story and ensured that I behaved in a respectful manner. Sensitive use of laddered questions, interwoven with the natural ebb and flow of our conversation, still enabled exploration of emergent hypotheses. Sometimes participants sought guidance in terms of what directions to take during interview and how deeply they should open up. My reply was to follow a direction that felt natural and to go as deep as they felt able, willing and comfortable with. This was relevant to all participants because some of the professional participants had both personal and professional experiences caring for a person with dementia or another relative.

While I attempted to build reciprocity and demonstrate genuine interest in participants' perspectives, research interviews contain issues of power (Mishler, 1986; Kvale, 2006). Holloway and Wheeler (2002) suggest it is a fallacy that researcher and participant work together in complete equality and yet the participant-researcher dyad is crucial to meaning-making. In relation to informal carers, I was concerned I could be perceived as occupying a powerful position and that this could place limits on participants' self-disclosures. I was also concerned I could be regarded with suspicion by health and social care participants, particularly in relation to how the findings could be used. To address these issues, I tried to ensure that all participants were active in sharing control of the interview. Consequently, similar to Brannen (1988) and Nunkoosing (2005), I experienced power as a two-way process. Lempert (2007: 248) refers to this as the "language and practice of give-and-take in research practice". Examples of participant control included participants choosing the location, time and context of interview. One participant (CFM02) preferred to sit in a high back chair in a particular room in her home for her comfort and another (CFM09) asked me if I minded if she smoked (I am a non-smoker), as it helped her relax. I also showed participants how to switch off the digital recorder if they wished to cease/interrupt recording. Such actions were important to sharing power and status differences. I found that many participants became absorbed in recounting their experiences. The CGT approach meant it was actually the participant who was powerful in terms of deciding what was meaningful to them. My experiences therefore support the contentions of Wise (1987) and Brannen (1988) that in interviews locus of control comes from the interrelation between the research topic, the interview approach and participants' statuses.

5.8.5 Sharing 'self' with 'other' in field-work

To enhance trust and disclosure, Mallory (2001) highlights the need for researchers to be willing to share their personal and professional values with participants and to explore differences. Similarly, Mills, Bonner and Francis (2006a) write that it is vital to theory construction that the researcher acts as participant partner and not objective analyst. This was a skilful process to manage because as a reflexive learner, I couldn't separate my nursing, researcher and personal selves. Many writers have acknowledged the difficulties of managing the blurred boundaries between roles (Wilkinson, 2001; Hand, 2003; Johnson and Clarke, 2003; Rager, 2005). For me, this was particularly manifested in relation to self-disclosure. I approached the interviews believing that to build rapport I could not be detached. Some self-disclosure and investment of personal identity might be required (Clarke, 2006). Prior to the interviews, I had not given in-depth consideration to the nature and/or limits of self-disclosure that might be involved. However, I quickly had to confront this issue. As a guiding principle, I followed the recommendation of Wilkinson (2001) to disclose my views only where relevant to the research in terms of conceptual connection to the substantive area. For example, many participants asked questions of me that were generally of three types: experiential, informational and professional.

Some participants asked if I had witnessed similar experiences to theirs or if I had personal experience of caring for a family member with dementia. Prior to the study, I had recently lost a close family member who, although not having a formal dementia diagnosis, had exhibited significant memory loss. I felt that sharing my experiences was necessary to demonstrate my genuineness and made me a 'real' person with a somewhat common frame of reference. A few informal carers asked me dementia specific questions. I felt that while these were sometimes designed to test my knowledge, in other instances the questions indicated that participants were seeking information. I addressed knowledge related questions that were within my scope of practice (An Bord Altranais, 2000) and where required, I provided the contact details of the information services of the Alzheimer Society of Ireland (as agreed with the Society). The experiential questions were generally posed in the pre-interview phase and contributed to the building of rapport. Informational questions were mostly posed in the emergence phase and did not impact on participant responses during the recorded component. Some health and social care participants asked for my professional opinion during recording. While meaning is co-created, I was very conscious that although the boundaries between my roles were blurred, I was present in a research capacity. So I chose a limited disclosure and then used a laddered question or probe to encourage the participant to elaborate on their perspective.

5.9 Ethical considerations

Thorne and Darbyshire (2005) highlight the researcher's moral obligation to justify a piece of research and the methods employed. This is a particular concern in the type of research described herein, which presents distinctive ethical issues and challenges relating to the study of human beings (Eide and Kahn, 2008). Consistent with Parahoo (2006), I believed every stage of the study had ethical implications. For example, the potential to exploit participants or provoke anxiety, distress or pain through inappropriate probing was ever present. The management of such concerns required an ongoing preventive process of evaluating harm and benefit for each participant. As a nurse, I adhered to the ethical research guidelines of our regulatory body (An Bord Altranais, 2007) and the ethical principles identified by the International Council of Nurses (2003) to protect people from harm.[35] In practice, ethical considerations (and related actions) did not resemble a formulaic adherence to actions 'done' or 'not done', 'to' or 'with participants. Instead, they were lived out in the four pillared approach (see below) I adopted to underpin the ethical conduct of the study. These pillars were designed to safeguard participants' rights and protect their well-being. As it turned out, they served a dual purpose by ensuring my ethical comportment to 'the encountered other' and contributing to the protection of 'my ethical

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[35] The six ethical principles are: beneficence, non-maleficence, fidelity, justice, veracity and confidentiality. In relation to the conduct of research these principles have been amalgamated into four participant rights: the right not to be harmed, the right of full disclosure, the right of self-determination and the right of privacy, anonymity and confidentiality (International Council of Nurses, 2003).

self'. This provided a degree of reassurance and supported Corbin and Morse's (2003) contention that research that is sensitively conducted and ethically directed benefits participant and researcher.

5.9.1 Pillar 1 – Considering the vulnerability of participants

As I was anxious that the research would provide valuable theoretical insights, it was necessary to access participants that could best provide an insight into the substantive area. However, I was also conscious that such participants could be considered potentially vulnerable and that exploring the sensitive topic of dementia could be challenging for them. Including vulnerable participants necessitates the inclusion of safeguards to protect their well-being, as ethically sound research must ensure the protection of human rights (An Bord Altranais, 2007; Hewitt, 2007). To maintain the autonomy of a vulnerable participant requires comprehension of the nature of vulnerability, descriptions of which are many (Weaver Moore and Miller, 1999; Sevick, McConnell and Muender, 2003). The literature suggests the following persons can be considered potentially vulnerable: those with diminished decision-making capacity, older adults, those subject to stigmatisation and marginalisation, those unable to protect their own rights and those with whom a researcher wishes to explore an emotionally sensitive topic (Lee and Renzetti, 1990; Weaver Moore and Miller, 1999; Council for International Organisation of Medical Sciences (CIOMS), 2002; Lott, 2005; Burke Draucker, Martsolf and Poole, 2009; Funk and Stajduhar, 2009). My liaison for the study from the Alzheimer Society of Ireland challenged my thinking in relation to considering the vulnerability of potential participants, while not allowing this to outweigh people's right to be heard. Calls for the voice of vulnerable persons to be heard and to inform service planning and delivery are increasing (Delaney, Keegan and McGee, 2002; Department of Health and Children, 2006; Keogh and Daly, 2009). However, actions preventing exploitation and protecting participant well-being can sometimes be perceived as paternalistic and questioned by those they seek to protect (Macklin, 2003; Hewitt, 2007). Langdridge (2004) concurs, referring to a growing conservatism in research that places fear of harm out of proportion to real risk that could result in certain populations being excluded from research participation. Instead, all human beings should be treated with respect and sensitive topics treated with care (Langdridge, 2004). In addition, research must maximise benefits and minimise harm (Lott, 2005). The second and third ethical pillars were used to assist me to balance these competing tensions.

5.9.2 Pillar 2 – Gaining ethical approval

Toffoli and Rudge (2006) highlight the role that ethics committees play in protecting participants and stimulating researchers' critical consideration of the ethical dimensions of research practice alongside the practical and procedural aspects. The questions posed on the ethics committee proposal form were fundamental to stimulating my identification of potential ethical considerations and strategies to address them. A meeting was held to review the draft ethics application prior to its submission. My principal supervisor and a representative from the Alzheimer Society of Ireland attended. This meeting advanced my sensitivity to the needs and rights of all those who live with dementia (including informal carers) and a number of minor modifications were made to the form in consequence. These included adjustments to the language and design of participant information sheets. Following submission of the ethics application, the ethics committee sought some minor amendments. The study was then granted full ethical approval by the Ethics Committee of the Faculty for Health Sciences, Trinity College Dublin.[36] In accordance with the ethical approval process, I wrote to the Chairperson of the Ethics Committee following the funded component to inform her of its continuation with the ongoing support of the Alzheimer Society of Ireland as gatekeepers.[37]

5.9.3 Pillar 3 – Ensuring participant well-being and protection

5.9.3.1 Gaining and ensuring ongoing consent to participate

Ensuring the right to self-determination can be complicated in research, particularly voluntariness, ensuring understanding and the informed consent process (Sevick, McConnell and Muender, 2003). The use of gatekeepers to facilitate access to the sample reduced my concern that a participant could feel coerced to participate in contrast to voluntarily choosing to participate. The decision to enrol/not enrol a potential participant in the study was reached jointly on meeting each person. Due to the open nature of data collection (Section 5.8.3), I could not predict what might crop up in our conversations. To facilitate self-determination and informed consent, all participants were provided with clear unambiguous information. When designing participant letters and information sheets, I considered their readability, content, font size, length and spacing. These were reviewed by my principal supervisor and the representative of the Alzheimer Society of Ireland. The finalised versions were informed by the guidelines of the Health Promotion Unit and the National Adult Literacy Agency (O' Brien, 2003) and the National Disability Authority accessible literature guidelines (National Disability Authority, 2005). Consent to participate was obtained in writing. The tick box consent form enhanced

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[36] A reproduction of the letter of research ethical approval can be viewed in appendix 14.

[37] Reproductions of these letters can be viewed in appendices 15 and 16.

readability and reduced the complexity of the decision-making process to a series of simple logically presented steps (Appendix 17). Two copies were completed and the second was retained by participants. This provided official recognition of participation as well as a written reminder of what participants were consenting to. I also used a process approach to ensure ongoing consent. This is an ongoing consensual process, which involves researcher and participant in mutual decision-making (Munhall, 1991; Usher and Arthur, 1998). Flexibility was therefore needed to re-evaluate and ensure a participant was not unduly discommoded and continued to want to participate. Importantly, each participant was reminded that they could withdraw without explanation at any time and that I could discontinue his/her participation should I feel it necessary to protect their well-being. No enrolled participants withdrew or were withdrawn.

Overall, no particular issues were encountered in relation to consent. However, three points are noteworthy. Firstly, participants were advised they could obtain a copy of their interview transcript should they so wish. Three participants requested this. One participant requested that I post the transcript to her place of work (AHPDO10), one to his home (CFM18) and the third (CFM10) asked me to hand deliver hers. Secondly, objective measures of capacity to participate were not used with the person with dementia because gatekeepers were requested to identify only those persons with dementia who were aware of their diagnosis and able to provide their own consent. Weaver Moore and Miller (1999) suggest that a significant other may promote comfort and a sense of protection for both. Therefore, the participant with dementia (PWD1) was offered the opportunity and chose to have his wife (CFM13) present and consent was obtained from both. Thirdly, all who indicated their interest in being in the study did participate with one exception. On contacting one gentleman (an informal carer), I recognised that he was volunteering to participate because he felt he should. He admitted that he would prefer not to participate if we had sufficient numbers. I therefore thanked him for his interest and assured him that, while it would be welcome, his participation was not essential to the completion of the study.

5.9.3.2 Ensuring privacy, anonymity and confidentiality

Langdridge (2004: 366) identifies anonymity and confidentiality, as two of the "most important ethical considerations in social science research". Such issues were addressed through meticulous attention to the handling of records (verbal, paper, digital and computer) and the concealment of participant identity. While known to me, anonymity involved ensuring that no participant could be identified by others. Gatekeepers were not informed of who chose to participate. At the time of enrolment, each participant was assigned a code by which the person was referred to from then on. Personal identifiers and references to people, places or institutions were removed from all transcriptions and participants were informed that my supervisors would potentially have access to the anonymised recordings. Some of the informal carer participants and the person with dementia felt so strongly that they stated that including their names was fine with them. However, I reiterated that the same conventions in relation to anonymity and confidentiality would apply in all cases and that no published material would identify participants. This was important because dementia experiences profoundly impact on multiple aspects of people's lives. While emotions might seem powerful at one time and motivate a desire to be named, this could change and a participant could later worry about compromising his/her anonymity.

Kaiser (2009: 1632) identifies the risk of deductive disclosure of participant identity as a primary consideration in research which involves the recounting of "detailed accounts of social life". Deductive disclosure occurs where people's traits make them identifiable in research reports. Confidentiality was consequently of central concern in this study and was upheld as follows. In the pre-interview phase, all participants were informed of the limits to confidentiality should any reference to potential malpractice or abuse be disclosed. It was pointed out that in such a case, I would have a professional obligation to refer any such reports to the appropriate authorities. I worried that this would limit the scope and depth of ensuing discussions. However, some participants (informal carers and allied health professionals) explained that this was reassuring rather than off-putting because it affirmed my professionalism and commitment to the protection of participants and those they cared for. Participants were assured of the confidential nature of the research and that I was the only person with access to their details and the master documents. Data were stored in keeping with the Data Protection Act (Government of Ireland, 2003) and consent forms identifying participant names and details were stored separately. Hard copies of documents were stored in a locked filing cabinet in a secure office. Computerised data and records were stored on one computer that was password protected in the secure office. Some transcripts were professionally transcribed by a transcriber known to the university department. When establishing transcription arrangements, we discussed the issue of confidentiality. She explained her confidentiality policy, arrangements for secure storage of digital recordings and her policy of erasing all digital media from her hard-drive following each transcription. Each recording was hand delivered by me and transferred directly to her computer. Any identifying references to people, places and institutions were removed during transcription and replaced with agreed terms, for example: 'Name of Person' or 'Name of Place'.

5.9.3.3 Ensuring the prevention of harm

Some topics including those that intrude deeply into people's lives or experiences contain a higher risk than others (Lee and Renzetti, 1990). Dementia is frequently identified as capable of raising powerful emotions and having the potential to cause distress. By doing what I said I would do, not probing beyond the stated research purpose and not abandoning participants once I obtained what I felt was useful, I demonstrated faithfulness to them. However, ethical decision-making can be difficult due to the emergent nature of research that requires participants to share intimate aspects of their lives (Hewitt, 2007). Pacing and individualising each interview to match the needs of those interviewed were central to ensuring the well-being of participants. Each participant was made aware that questions were requests for information but there was no expectation of having to respond. If indication of upset emerged, interviews would either be: discontinued, discontinued and resumed if and when a participant indicated readiness or resumed but with a change of topic. This occurred on a few occasions. CFM01 exhibited body language (wringing her hands and looking for a tissue in her pocket) that indicated upset but she insisted that the recorder not be turned off. As the interview continued, she visibly relaxed, leaning back in her armchair and laughing. Some participants cried (CFM04, CFM06, CFM19 and CFM20). On these occasions I turned off the digital recorder and sat with them. All insisted that recording be recommenced after a short break. If required, participants were provided with information on support services available through the Alzheimer Society of Ireland. As informal carers were accessed through the Society, the majority were very aware (if not users of) the services and supports. Participants also had my contact details (e-mail and office telephone number) should they wish to discuss any aspect of the research or to withdraw. No participant availed of this opportunity.

According to Corbin and Morse (2003: 388), it is "the very essence of trust and conversational intimacy that creates both the potential threats associated with unstructured interactive interviews and ... makes them potentially therapeutic, as well as essential data collection tools". Engaging in conversation with someone who is non-critical and shares a common and genuine interest in your viewpoint can be beneficial (Kvale, 1996; Eide and Kahn, 2008). Hutchinson, Wilson and Wilson (1994) also identify participant benefits to qualitative research including that of catharsis.[38] Overall it is difficult to ascertain if there was benefit for participants. Many expressed a wish to affect change or positively influence someone else's life by participating. Others commented on their relief at having stopped to think about their experiences, verbalise

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[38] The benefits of qualitative research participation listed by Hutchinson, Wilson and Wilson et al (1994) are that interviews: 1. serve as catharsis, 2. provide self-acknowledgement, 3. contribute to a sense of purpose, 4. increase self-awareness, 5. give a sense of empowerment, 6. promote healing and 7. give voice to the voiceless and disenfranchised.

their story and engage in sense-making. All thanked me for being included and the opportunity to help. I had follow-up contact with: CFM10, CFM18 and AHPDO10 to arrange delivery of their requested interview transcripts, CFM05 to ensure she had access to information about an issue that came up in our interview and I spoke by telephone with other participants to thank them for participating.

5.9.4 Pillar 4 – Considering my vulnerability as a researcher

Both Lee and Renzetti (1990) and Corbin and Morse (2003) remind us that research can be very demanding of, if not threatening to, the researcher. Participant responses are social constructs, recounted in the particular context and consequently neither researcher nor participant can predict the course of an interview (Clarke, 2006). I found being a researcher a double edged sword. Engaging in the collection of data was sometimes an exhausting and emotional experience because participants shared their joys, tears, anger and frustrations. For example, I was overwhelmed with loss and frustration for participant CFM04 who was coping with what she perceived to be the loss of her known life, while simultaneously loosing the person she relied on for support. My experiences are similar to Rager's (2005) description of compassion stress in researchers. However, my reactions sensitised me to listen to participants' accounts in a way that a dispassionate ear might have precluded. The simultaneous management of the interview, ensuring participant well-being and my awareness that an ethical issue might arise that would require intervention were particularly difficult. This happened only once where I felt the participant (CFM05) required specific informational support.[39] A number of writers have identified the affective impact of data collection on the researcher where the subject matter is deemed sensitive (Johnson and Clarke, 2003; Beale et al, 2004; Lalor, Begley and Devane, 2006). It is consequently recommended that support mechanisms may be needed for researchers in addition to those for participants (Parnis, Mont and Gombay, 2005). I used a number of strategies to ensure my well-being during this study:

1. I completed my field-notes immediately after each interview. While recording contextual interview detail, they were also cathartic because they helped me to work through my immediate emotions.
2. I tried to leave time between interviews to enable me to process what had occurred. This was not possible on two occasions. It was during these times that I perceived the greatest emotional impact.

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[39] The issue in question was acted on in the context of the interview and following discussion with my supervisor a follow-up call was made to ensure that the participant intended to access the available support resources.

3. My principal supervisor listened to the early interviews (with participants' knowledge). Our subsequent conversations were a means of support and an invaluable conduit to enable me to surface and work through my emotions.
4. Some interviews were conducted in unfamiliar geographical and domestic contexts and I experienced some anxiety on one or two occasions. To manage this and ensure my physical safety, I arranged to phone my principal supervisor just before entering a participant's home and on leaving the interview. This was done without compromising participant anonymity, as I informed my supervisor only of the general area to which I was travelling.
5. While I carried the voices of the participants with me during the CGT process, I was able to contain their spill by learning to accommodate the research in relation to other parts of my life and through memo writing.
6. Finally, as a member of the PhD support group in my affiliated School, I accessed the monthly meetings to hear others' research stories and to receive support for mine.

5.10 The analytic process

> "... insights into data do not occur haphazardly, they happen to prepared minds during interplay with the data" (Corbin and Strauss, 2008: 32).

The procedures used to inform data analysis were consistent with the CGT methods described by Glaser and Strauss (1967) and Glaser (1978, 1992, 1998, 2001, 2003, 2005). These were: simultaneous collection of data (Section 5.8) and engagement in constant comparative analysis, coding (substantive and theoretical), identification of categories and their properties, memo writing and theoretical sensitivity (Jeon, 2004).

5.10.1 Asking questions of the data

Coding is a critical factor in the production of a CGT because it "gets the analyst off the empirical level by fracturing the data, then conceptually grouping it into codes that then become the theory which explains what is happening in the data" (Glaser, 1978: 55). During data analysis, I continually asked the following of the data (in addition to the guiding research questions (Section 5.5)):

- What is this a study of?
- What category does this incident indicate?

- What property of what category does this incident indicate?

(Glaser, 1998: 123).

While the description of coding and theory formulation may appear linear, the lived process was far from such. Similarly, McGhee, Marland and Atkinson (2007) refer to grounded theory as concurrent, iterative and integrative in nature. In coding for process, continually questioning the data was essential for two reasons. Firstly, continual questioning maintained my theoretical sensitivity and sensitised me to concentrate on patterns within incidents. Secondly, it prompted me to recycle through the components of analysis in an effort to produce a coherent, dense and parsimonious theory (Holton, 2007; Cutcliffe and Harder, 2009). At times the overlapping (yet systematic) nature of CGT analysis was uncomfortable, if not difficult to manage. I was anxious that I would drift from conceptual abstraction to logical elaboration (Glaser, 1998). If this had occurred, it would have risked grounding the theory in conjecture and not in the data. However,

> "my awareness of this risk [kept] me focused and the recycling and simultaneous nature of the CGT methods ensure[d] that the emergent theory is in fact grounded in, while transcending the data" [L Daly, Memo, 24th May 2007].

5.10.2 Use of computer software

The transcribed interviews and field-notes were imported into the NVivo 7 (Q S R International Pty Ltd, 2006) computer package. I attended an eight hour training course and purchased the licence to install and use the software on my personal computer. The programme was used to: store, manage and interrogate data, record memos, create a record and track the research process and the emergent findings. However, use of the software was not plain sailing. I encountered some frustrating deficits in its efficiency, including: inadequacies in the modeller, a tendency for the programme to scramble what was visible, if a particular area of the screen was clicked on, and an annoying inability to view data on the whole screen. An over reliance on this software could consequently have been stultifying and produced "description and not integrative, conceptual, abstract theoretically coded theory" (Glaser, 2005: 38). Instead, I avoided this risk to conceptualisation by using the software to support and not substitute the cognitive and manual analysis processes described below.

5.10.3 Beginning conceptualisation - open coding

Consistent with the constant comparative analysis method, coding began following the first interview. I initially read the transcripts and field-notes repeatedly, while listening to the interview recordings. This facilitated my early immersion in the data. Manual line by line open coding, the first component of substantive coding, was carried out to identify processes and assign initial open code labels by using a combination of in vivo and my own words (Appendix 18). This focus on coding, what Charmaz (2006) refers to as identifiable actions, was extremely helpful to begin to visualise interrelated processes in contrast to static isolated topics. As coding proceeded, frequently the same data extract was assigned a number of codes (Table 5.1). This is expected because interactions are rarely circumscribed and devoid of context (Woods, Priest and Roberts, 2002). Instead, people communicate and act in complex ways so that one speech may refer to multiple concepts. Participants' responses were conceptualised as independent and simultaneously connected "like the two sides of a mirror" (Maijala, Paavilainen and Astedt-Kurki, 2003:45). As issues and concepts began to emerge, they were explored in the field and the data. I compared incident to incident, incident to concept and concept to category (Glaser and Strauss, 1967; Glaser, 1978, 1998, 2001, 2003, 2005). This was critical to inform the following interview, theoretical sampling and the simultaneous expansion and delimitation of the theory (Glaser, 1998).

Table 5.1 Exemplars demonstrating open coding

Participant code	Exemplar	Open code(s)
CFM01	Oh we had to do everything on our own! No help! No help! No assistance, there was absolutely, there was nothing	Being abandoned by healthcare system Fighting for care
CFM05	It is a really big battle to find out anything, huge battle ... I have a friend who's a psychiatrist and I mentioned it to him and he actually which was just a personal favour he contacted a nurse	Finding information Seeking help
AHPDO2	Isolation, I had two or three very good friends who were very, very supportive, right the way through, I say two or three, I might have had four or five but other friends, they couldn't cope. And it was rather hurtful that they never phoned, they never offered to take him out or sit	Being abandoned by friends and colleagues
CFM18	I am an expert in one individual which is (participant's wife). What I have found out about Alzheimer's is that there are not two people who have the same, who are affected in the same way	Focusing on other Becoming an expert No two people are alike

Working from the verbatim transcripts for a time muddied the waters. This was because I had transcripts of entire interviews. While in CGT 'all is data' (Glaser, 2001: 145), Glaser (1998) does suggest caution in relation to using verbatim transcriptions of entire interviews. This could infer that I probably had a lot of data that may not have been relevant to the problem of concern. However, I chose to digitally record interviews and transcribe them verbatim because I learn best through simultaneously listening and seeing. I could also replay an interview where I needed to clarify the intonation and meaning(s) behind a word or set of words. At the outset, I was additionally concerned that I may not have had the skills to sufficiently document participants' responses without recording them. I worried I would miss data or forget something important. Despite possessing professional communication skills, it would have been dangerous to assume that I possessed sufficiently developed research interviewing and data recording skills. It took time for me to develop and become confident in such skills.

Managing the verbatim transcripts led me to introduce an intermediary stage between manual open coding on the transcript margins and entering open codes into the software package. I constructed an open code list for each participant (Appendix 19). Using the lists, I could quickly refer backwards and forwards between and within interviews to identify and examine codes in relation to their complimentarity and contradictions. This assisted me to search for latent patterns and relevancies more efficiently, while delineating extraneous codes. As I became more selective and while nothing was discarded, not every line received a code unless relevant, or became relevant, as I theoretically sampled the data for newly emergent concepts. I became more focused as I coded on in the subsequent interviews. This enabled me to avoid over fracturing data and the production of copious open but irrelevant codes. At this point, I attended my first Grounded Theory seminar with Dr B Glaser (April 2007). The seminar helped me to clarify my understanding of the CGT methodology and I gained sufficient confidence in its tenets to "trust to the emergence of a problem while suffering the vacuum of it in the beginning" (Glaser, 1998: 127).

5.10.4 Emergence of the main concern and core category

Cutcliffe (2005) suggests that ensuring a study achieves conceptualisation may support intellectual entrepreneurship within qualitative research. This supports Morse's (1994) call to abandon timidity in favour of risk taking to produce theory. As there was sufficient data to support the presence of dementia-related stigma, this could have triggered a logical drift to stigma being the issue of central concern. However, using CGT I appreciated emergence would then have ceased. This is because the attractiveness of presenting all one knows about something, in this case about stigma, is exciting and easier to achieve than remaining open to the emergent (Glaser, 2001). My anxiety to prevent such a drift has I imagine kept many a CGT researcher awake at night. However, by remaining open to multiple theoretical directions (Charmaz, 2006), it emerged that stigma was limited in terms of providing a theoretically robust explanation of the principal concern of participants in this study and the actions they engaged in to address it. Rather than being the primary problem, stigma was identified as an underpinning facet of the originating problem.[40] Thus, by using the CGT methodology and continually questioning the data, it emerged that participants were concerned about what was named the problem of 'Living on the fringes'. Having identified this problem, the category of 'Sustaining our place' quickly surfaced as the core category. This category demonstrated the greatest integrative and maximum explanatory ability in the emerging theory. The core category in CGT relates to all other categories and it accounts for most of the behaviour in the substantive area being researched (Glaser, 1978, 1998). As experienced in this study, identification of the core category can take time but "the full power of grounded theory comes with staying open to the emergent and to earned relevance" (Glaser, 2005: 1).[41] The recognition of 'Sustaining our place' as the core category was consequently a significant point in the study.

5.10.5 Advancing conceptualisation – selective coding

Having identified the core category, I moved to begin selective coding (the second component of substantive coding). This is a crossing over and delimiting level of coding, which involved giving stable patterns fitting names to explain informal carers' main concern and how they addressed it (Christiansen, 2007). I began to selectively code at a more conceptual level of abstraction than the initial open codes. Conceptualisation has been described as "an intuitive or non-discursive process that involves apprehending an idea" (Pesut and Johnson, 2007: 115). Concepts and their related incidents from the open coding process were compared with each other as new incidents and more data were collected. In some instances early codes were merged and/or renamed into higher level conceptual codes (Table 5.2). The codes with their data extracts were organised to form the theoretical categories and properties of categories. These were then explored for their potential inter-connections and points of digression. I searched or mined (Charmaz, 2006) for conceptual gaps to explore in ongoing theoretical sampling. Through ongoing sampling, the categories were "expanded, diemensionalised and delimited" (Stern, 1994: 122). Throughout, I continued to run the data open and I frequently returned to review, confirm, revise and explore my conceptualisations (Glaser, 1978, 1998). As

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[40] See Chapter 1 Section 1.3 and Chapter 10 Section 10.4, for an explanation of how stigma relates to the theory of 'Sustaining Place'.

[41] It was around this time (October 2007) that I attended my second CGT seminar with Dr B Glaser and other students of the methodology.

hypotheses surfaced, interrogation of the data was both manual and computerised and consequently not accomplished in a neat or easily explained manner.

Table 5.2 Examples of code name changes during selective coding

Original code name	Date of code name change	Revised code name
Making associations – labels & images	28.06.07	Perceptions of dementia – labels and images
Seeking ethical care	06.03.08	Seeking humanising care
Surveilling	06.03.09	Monitoring care
Insider knowing	16.03.09	Developing expertise
Protective encircling	20.03.09	Protective enfolding

Thus, using CGT, amendments, alterations and revisions were ongoing and I came to understand the complexity of the analytic experience. As the latent patterns became much clearer, I began to sample, compare and integrate the literature as a further source of data in the constant comparative analytic process. This literature introduced additional concepts such as meaning making following life disruptions. However, potentially relevant concepts were always considered with caution, so as not to allow the literature to force the data to fit or vice versa. Instead, if a concept had relevancy to the emergent theory, using the CGT methods would enable this to emerge. Selective coding continued until I saturated the categorical structure (Appendix 20).[42] This occurred following the eighteenth informal carer interview but I continued to collect data for a further two interviews. Theoretical saturation is questioned by some, including Dey (1999). However, such writers may hold a different understanding of the term to that intended when used in CGT. Theoretical saturation in CGT infers that no additional data is emerging with which to develop categorical properties, as opposed to seeing the same patterns over and over (Glaser and Strauss, 1967; Glaser, 2001; Holton, 2007; Chen and Boore, 2009). Therefore, theoretical saturation is tentative because there is always the possibility of

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[42] At this point (October 2008), I attended my third and final CGT seminar at which my conceptualisations were discussed and endorsed.

new data being encountered and comparatively analysed. The generation of a CGT consequently contains the potential to be an inherently ongoing modifying process.

5.10.6 Use of memos

Memo construction was critical in the development, elaboration and integration of categories and my reflexivity (Appendix 21). Memos are flexible narrative devices that record a researcher's developing ideas and thinking in relation to the social world of research contexts (Lempert, 2007; Montgomery and Bailey, 2007). Using memos leads to advanced levels of abstract thought and the development of the concepts discovered within the data to the conceptual level (Montgomery and Bailey, 2007; Chen and Boore, 2009). They also enabled me to work out the articulation of the relationships between and among the core category, sub-core categories and their constituent properties. The continuous process of memo construction was critical to refining and tracking the emergent theory. Memos were descriptive and short in the beginning, bearing witness to my inexperience. However, their volume, complexity and length grew with time and practice. Memo construction could occur at any time due to the preconscious processing pivotal to conceptualisation in grounded theory. Because of this, I carried a notebook to record my ideas. The memos were stored in the NVivo software (Q S R International Pty Ltd, 2006). Each was titled, dated and importantly remained open, so it could be added to or amended as theory generation proceeded. I amassed a memo pile as the study advanced, which I began to sort to help formulate the writing of the theory. I also placed a large AO sized sheet of paper on a wall onto which I placed removable coloured sticky notelets with category code names. I used this to create a visual representation of the emergent theory in a dynamic three dimensional format. I could manipulate the components as conceptualisation and theory integration proceeded. Sorting the memos in conjunction with this process enabled me to conceptualise the theoretical structure. This enhanced the delimitation, densification and saturation of the theory (Glaser, 1978).

5.10.7 Reflexivity

Krieger (1991: 89) writes that "the pot carries its maker's thoughts, feelings, and spirit. To overlook this fact is to miss a crucial truth, whether in clay, story or science". With this in mind, I documented my insights and experiences at various points in the study. These notations were incorporated into the memos described above that later formed the substance of the writing of the theory (Chapters 6-9). Alternatively, sometimes this reflexive engagement involved me interviewing myself. These were not digitally recorded. Instead, I would sit quietly and question myself in relation to a concept, category or a property thereof. This questioning involved me considering what the data was saying about the category or property and how this compared or contrasted with my experience and later with the available literature. Alternatively, these self-interviews sometimes related to a methodological aspect of the study, for example: my approach to or my use of self in interviews and in relation to particular ethical considerations. On other occasions, it was a more in-depth personal reflection and analysis around the emotions I was feeling. Illustrative examples of this were when I felt angry about informal carers' experiences of marginalisation within health and social care systems or I was upset when considering the social isolation and hurt that occurs where friends and other social contacts increasingly withdraw. It was important to analyse my emotions at such times to ensure that they did not threaten the integrity of CGT process.

Personal experience was linked with theoretical sensitivity and a positive source of data in Glaser's (1978, 1992) early texts. More recently however, Glaser (2001) considers that reflexivity could distract researchers from data and potentially lead to description. Similarly, Finlay (2002), while promoting purposeful reflexivity, stresses the avoidance and over preoccupation with the self as it could risk skewing findings. As a result, I was conscious of the need to interrogate my subjective experiences to achieve a purposeful analysis (Finlay, 2002; Neill, 2006), while simultaneously not allowing my history to force or distort the data. To this end, I used reflexivity and the process of memoing in two ways. Firstly, I used them to enable me to understand my effect on the research and the social processes influencing the generation of the data (Hall and Callery, 2001; McGhee, Marland and Atkinson, 2007). Secondly, I used them to enhance my theoretical sensitivity by acknowledging my pre-understandings, which I then consciously examined but avoided incorporating unless found to have theoretical relevance.

5.10.8 Theoretical coding and theory integration

According to Glaser (1998), CGT is a third level conceptual perspective analysis. Theoretical coding is the third and highest level achieved through sorting the theory. It is the stage in which the fractured data is woven together through the use of a coding framework (Boychuck Duchscher and Morgan, 2004). Using an appropriate theoretical code assists the researcher to sustain the conceptual level when writing up the theoretical components and the relationships between them (Holton, 2007). Early on I struggled to understand theoretical codes. I felt that this was due in part to being a nurse without an extensive grounding in sociological or other sensitising concepts. This was a concern until I realised that this 'deficit' was a positive because it prevented me from imposing a pet code that could force the emergence of a theoretical structure. Instead, I learned the significance of Glaser's (1978: 72) statement that theoretical codes conceptualise "how the substantive codes may relate to each other as hypotheses to be integrated into a theory". In-depth study of the theoretical codes suggested by Glaser (1978, 1998, 2005) combined with broad engagement with a variety of literature enabled me to apprehend the possibilities of the available codes. I began to compare relationships between categories using different theoretical codes, so as to advance the degree of theoretical abstraction. The theoretical code that eventually demonstrated best fit was that of a basic social process. A basic social process has a minimum of two stages, occurring over time, involving change and with discernible breaking points between each stage (Glaser, 1978). As will be seen, (Chapters 6-9) this theoretical code was the most effective in terms of theoretical integration and provided form to the CGT of 'Sustaining Place'.

5.11 In summary

This chapter outlined how the CGT methodology described by Glaser and Strauss (1967) and Glaser (1978, 1992, 1998, 2001, 2003, 2005), and methods consistent with this approach, were used to inform the research process. In recounting my experiences, I presented my lived reality and tried to not engage in what Stanley and Wise (1983) refer to as the hygienic representation of research. I have illustrated the challenges I encountered to enable understanding of how the theory was conceptualised and the learning engaged in along the way. The substantive CGT of 'Sustaining Place' will be presented in the following four chapters.

Chapter 6 Overview of the Theory of 'Sustaining Place' and 'Unsettled Place'

> "Illness creates an alien world for its citizens. Maps of the person's previous homeland are useless for understanding and navigating the new world's strange terrain, and one's compass spins out of control because no orientation points can be found" (Hess, 2003: 137).

6.1 Introduction

This chapter and those that follow will present the theory conceptualised in the course of this study.[43] The substantive CGT of 'Sustaining Place' is a basic social process engaged in by carers of persons with dementia to address their concerns in relation to the problem of 'Living on the fringes' (Chapter 1, Section 1.3). In this chapter, I will provide an overview of the theory of 'Sustaining Place' and present its first component, 'Unsettled place'. The chapters that follow will present the other three components of the CGT, which are: 'Threatened place', 'Sustaining our place' and 'Sustained place'.

6.2 'Sustaining Place': an overview of the theory

The theory of 'Sustaining Place' refers to a process engaged in by informal carers of persons with dementia, to address the problem of 'Living on the fringes'. To recap, 'Living on the fringes' refers to an alteration of the informal carer's relationship with and place within his/her life-world. Crucially, the experience of 'Living on the fringes' also creates equal concerns for informal carers regarding the place of the person with dementia. In this theory, the word 'place' is used to denote an existential phenomenon referring to an individual's situatedness within and among other people, organisational and societal structures and spaces. A sense of place is experienced and interpreted by informal carers in the context of inter-relational encounters, or disruptions thereof. The need to engage in 'Sustaining Place' (Figure 6.1) occurs when informal carers experience a growing threat to their sense of place and that of the person with dementia. The data, from which this theory was conceptualised, suggest that it is not only the day-to-day

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[43] The following abbreviations will be used when presenting participant quotations: CFM for informal carer, PWD for Person with dementia, AHPDO for Allied Health Professional and Disability Organisation participants and FNM where extracts from fieldnote memos are referred to. Of note, the following AHPDO participants were or had been informal carers: AHPDO2 and AHPDO6.

minutiae of caring that are of concern to carers; it is also the wider contexts and interactions within which such care is lived out. The literature mainly deals with related issues in terms of those with illnesses and the resultant disruptions to their worlds. However, 'Sustaining Place' hypothesises that the life-worlds of both the informal carer and the person with dementia are affected (in somewhat similar and yet different ways) due to threats to their sense of place. For example, informal carers in this study highlighted spatial and relational alterations in relation to the following contexts: familial, social, occupational, financial, and health and social care. It is as if the carer and the person with dementia become disqualified from their previous lives, while simultaneously being propelled into new or altered relational encounters. There is a discontinuity with what has gone before, not only because of the inherently progressive nature of dementia but also because of other people, organisations and societal reactions to its presence. As a basic social process, the theory of 'Sustaining Place' describes informal carers' efforts to resolve the encountered problem on behalf of themselves and the person with dementia.

Figure 6.1 An overview of the theory of 'Sustaining Place'

'Sustaining Place' has four components:

- 'Unsettled place', in which informal carers appreciate a sense of difference in taken for granted life-worlds,
- 'Threatened place', in which there is a disruption to belongingness, purpose and directionality, culminating in the recognition of a need to take action,

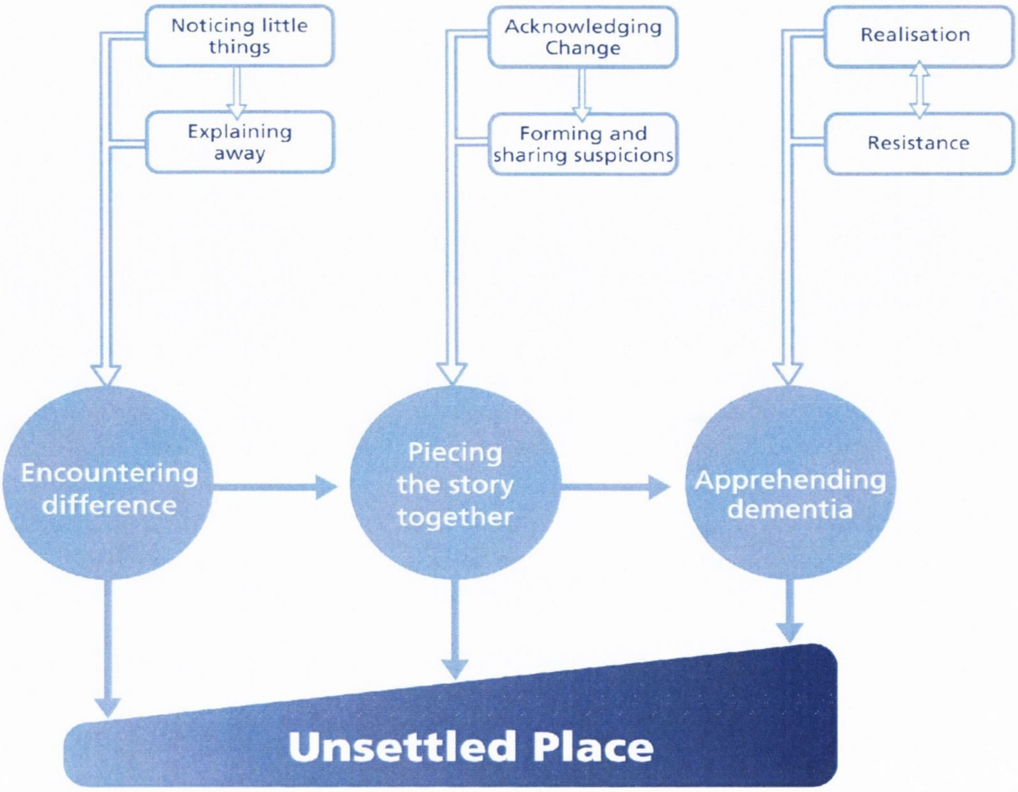
- ‘Sustaining our place’, in which informal carers engage in actions directed towards sustaining their sense of place, and that of the person with dementia, in the contexts of their life-worlds and
- ‘Sustained place’, which is attained if the problem of ‘Living on the fringes’ is successfully addressed by informal carers and a sense of place is restored.

Although the theory may at first glance appear to be linear, there is a feedback system in operation between the components that follow ‘Unsettled place’. If ‘Sustained place’ is achieved, the carer may be tipped back to ‘Threatened place’ by newly encountered and/or re-encountered threats to place and then move again to ‘Sustaining our place’. Therefore, while an informal carer may move through the theory in a linear manner and remain in ‘Sustained place’, it emerged from this study that informal carers are more likely to move back and forth between some components (Figure 6.1). The data also illustrate that some informal carers may never reach ‘Sustained place’. Instead, they may move between ‘Threatened place’ and ‘Sustaining our place’ for the duration of the informal caring role. The basic social process of ‘Sustaining Place’ is therefore dynamic and actions and sub-processes engaged in by informal carers can occur in relation to sequences of ‘Sustaining Place’. The remainder of this chapter will present the first component of ‘Sustaining Place’, which is ‘Unsettled place’.

6.3 Introduction to ‘Unsettled place’

‘Unsettled place’ involves the time from which the informal carer begins to notice a difference in the person up to the recognition that this change is due to dementia. Krull (2005) writes that the onset of dementia is insidious, incorporating: cognisance of alteration, suspicion of a ‘medical anomaly’ and the search for a diagnosis. Consequently, because ‘Unsettled place’ incorporates the onset of dementia, this component demonstrates some similarities with the opening stages of some of the temporal constructions of informal dementia care reviewed in chapter three (Section 3.5.4). However, the actions of carers in ‘Unsettled place’ (Figure 6.2) relate to informal carers’ actions in respect of ‘Sustaining Place’ and are not conceptualised in terms of a trajectory of care-giving or dementia progression.

Figure 6.2 'Unsettled place'



In 'Unsettled place', the growing sense of being unsettled is largely contained within the informal carer-person with dementia dyad. Participants' narratives demonstrate that dementia causes a disruption to their status quo. This is because prior to the presence of dementia, carers are generally pursuing a life-course that is individual and yet connected, by virtue of the particular relationship, to the person with dementia. Dementia can intrude into the life-world of an informal carer insidiously over a prolonged period of time. Alternatively, dementia can make its presence felt more quickly, for example where incidents happen in which the person with dementia makes an obvious mistake, such as when driving or in an occupational setting. Regardless of the means of arrival, the intrusion of dementia-related difference does occur and the problem of 'Living on the fringes' announces its presence to the informal carer. When this happens, there is a growing sense of alienation from some or all aspects of an informal carer's known life-world. This results in an unsettling disruption to a carer's sense of existence in and relationship with this life-world. The data suggest that regardless of the time it takes for this to occur, informal carers experience the properties of 'Unsettled place', although individual informal carers may move more quickly through some of its aspects. 'Unsettled place' is comprised of the following properties: 'encountering difference', 'piecing the story together' and 'apprehending dementia'.

6.4 'Encountering difference'

This category relates to the initial recognition by carers of early difference(s) in a significant other. Dementia is not yet identified as a potential presence, or it may be that it is not consciously acknowledged as a potential explanation for what is noticed. At this early point, the vibrations of 'Unsettled place' may be felt. However, the problem of 'Living on the fringes' is not a defined concern. 'Encountering difference' has two indicators: 'noticing little things' and 'explaining away'.

6.4.1 'Noticing little things'

Almost all of the informal carers in this study in some way referred to 'noticing little things' as an early precursor to constructing a definitive awareness of 'Unsettled place'. Little things in this instance refer to subtle differences that are noted in the person with dementia, for example in terms of their personality or engagement in familiar actions and activities. At first the differences are not very intrusive. They do not cause noteworthy impacts on ways of being or relating and consequently to an overall sense of place, as the following extracts illustrate:

"First thing I, well they were only little things..." (CFM10)

"Ehm, first sign, we noticed she [participant's mother with dementia] did different little things, we noticed she did different things at home." (CFM15)

Over time differences in the person with dementia begin to register with the informal carer who recognises them as indicators of something. This can occur in real-time or retrospectively, despite Wilson's (1989b) finding that in her theory this was a retrospective action only. There is however a 'then' point, at which time informal carers' narratives suggest that little things start being consciously noticed, as these participants explain:

"... and then, I noticed too that he [participant's husband with dementia], he would leave doors open he would leave the car door open, stuff like that ...." (CFM07)

"Things went along swimmingly then, my husband was older than myself and about 1979 he started losing things." (AHPDO2 who was both an informal and formal carer)

Informal carers' narratives suggest that variances occur in the ways that these differences are noted, for example: in advance, alongside, after or in the absence of noticing by the person with dementia. In some instances, onward movement through 'Unsettled place' is delayed. Little changes that could propel the informal carer towards definite suspicion of dementia may recede. This is a feature with early stage dementia and also with particular types of dementia, for example vascular dementia, which is characterised by a stepwise progression (Stephan and Brayne, 2008). Sometimes, the person with dementia may cover up differences, as illustrated by this daughter of a person with vascular dementia:

"She [participant's mother with dementia] just, I think she just blanked it out and never talked about it, she didn't mention it, she would just say that "I'm getting really forgetful"." (CFM05)

Alternatively, the person with dementia or the informal carer may be saying that things are ok, which alleviates the unsettling nature of 'noticing little things' and provides reassurance, as suggested here:

"And even when I would say something to my mum, she'd say I was imagining things as well." (CFM17)

It may also be that closeness to the person with dementia can sometimes act as a buffer, or it may be that noticing is easier for someone who knows the person but has less contact, such as another family member or close friend. Sometimes, to notice differences, an informal carer may need to witness the person in unfamiliar territory where the person with dementia may experience more pronounced difficulty. For example, a number of participants identified that they noticed differences while on holiday:

"Because he [participant's husband with dementia] was out of his normal routine, out of his own environment, he wouldn't eat the food there, although it wasn't very different really." (CFM02)

"Well it [noticing] was really, as I said when we [participant and his wife] were out in Spain." (CFM08)

'Noticing little things' tends to be cumulative. At this point, the differences are still not enough to trigger immediate associations with dementia. It is only with successive 'noticings' that the informal carer is triggered into the next form of action, 'explaining away', stimulated by the beginning perception of an unsettling of place.

6.4.2 'Explaining away'

As the instances of 'noticing little things' start to accumulate, their presence becomes more intrusive. An informal carer, and sometimes a person with dementia, may try to explain away what is noticed as a search for a reason or reasons for what is occurring begins. This action is similar to the nature of: explaining referred to by Wuest, King Ericson and Noerager Stern (1994) and Galvin, Todres and Richardson (2005), 'discounting and normalising' referred to by Wilson (1989a, 1989b), 'seeing and exploring signs' identified by Perry (2002) and normalisation (Carpentier et al, 2008), wherein plausible accounts are drawn on to account for differences in behaviours. However, it differs in other ways: for example, in 'Unsettled place' explanations used are those which are most desirable and/or tolerable in a hierarchy of acceptability. While the search for a satisfactory and acceptable explanation might ultimately be time wasting, for some informal carers it is necessary and may suggest a form of self-protection. It may be that an informal carer is unready to face what may already be subliminally suspected. Explanations that do not concur with those desired may consequently be disregarded, or stimulate a direction change in terms of finding an alternative. This contrasts with Wuest, King Ericson and Noerager Stern's (1994) assertion that explaining relates to a failure to note the reason for changes. Early on in 'Unsettled place', the carer uses commonsense rationalisations to 'explain away'. Thus, initially what differences are noticed and explanations used may be related to conditions of life and particular social circumstances familiar to the informal carer and person with dementia, as illustrated by the following participants:

"... going back to what I thought it was at the time, I actually at the very beginning thought she [participant's mother with dementia] was just very stressed out, and that if she had less stress in her life, and I was saying that to my father like, if she has less stress in her life, she wouldn't be forgetting ..." (CFM04)

"And I used to answer thinking that maybe she [participant's mother with dementia] wasn't paying attention or something."(CFM17)

For those persons with dementia who are older, the informal carer may relate early differences to ageing. The normalisation of dementia-related changes has been noted previously (Carpentier et al, 2008). In such instances, to informal carers differences noted are a natural expectation and consequently more acceptable, as shown here:

"... he [participant's father-in-law] was getting more and more forgetful but we put it down to age and those kind of, because in that stage he was in his late seventies and all this kind of thing." (CFM11)

This explanation will not however suffice for the younger person with dementia, where there may be an expedited process of 'explaining away' because differences may be more pronounced or have greater impacts. Where this happens, an informal carer may move more quickly through the categorical property of 'encountering difference', lending greater credence to a more pronounced sense of 'Unsettled place'. In contrast, fear of the possibility of dementia can be another stimulus for 'explaining away'. One participant referred to this in the following way:

"I think it [dementia] makes people fearful of bringing people out into the bigger picture." (CFM04)

Fear is sometimes greater in those who have previous knowledge of dementia. Alternatively, where there is previous experience of dementia, an informal carer may not engage in 'explaining away', or only minimally so, and move more directly to 'piecing the story together' or 'apprehending dementia'. There is some suggestion in the data that stigma may be one cause of 'explaining away' and that this is connected to the fear that one might lose social standing and that how one is then perceived by others may change. For example, one daughter carer explained:

"... well in the beginning, as I say, I just felt a little bit ashamed then, let say right at the beginning that my mother, "oh, god, what's my mother is getting" you know, what am I'm gonna tell the people." (CFM10)

This was also noted by some of the allied health and social care professionals:

"... that's one side of it, that the patient or the sufferer or the person is aware of a difficulty in not wanting to divulge it [potential dementia], because it may interfere with their social or professional roles or their working life, or how they're perceived. And then the other side of it is that the family may look on it in the same way, that this may have a big, great impact both socially and from a work perspective and family role, all that sort of thing. So they will hedge it." (AHPDO9)

‘Explaining away’ may be an early coping mechanism, which provides sufficient space and time for an informal carer to ready themselves to face the approaching apprehending of dementia. However, this action can delay dealing with dementia-related differences and contribute to a growing sense of ‘Unsettled place’ when explanations cannot be upheld by an informal carer. At a certain point, ‘explaining away’ becomes both untenable and unhelpful and gives way to ‘piecing the story together’, which entails focusing on what is, rather than what would be preferable.

6.5 ‘Piecing the story together’

Here the sense that something is seriously wrong is increasing and more consciously acknowledged. Differences are now identified as indicators of permanent change, which continue to build crescendo like. Instead of searching for improbable explanations, informal carers now work in an engaged manner with the indicators of change. Bit by bit they link individual incidents and/or changes together, attempting to consider what is occurring in terms of the person with dementia’s life and their own. Informal carers begin to create personal meaning rather than externalise the problem. Where there may have been a pushing away of what is experienced, there is now openness to working with what is happening. This approach builds to an overt suspicion of possible dementia, particularly where indicators of difference transgress what Gubrium (1986: 100) refers to as “social limits and tolerances”. The indicators of ‘piecing the story together’ are ‘acknowledging change’ and ‘forming and sharing suspicions’.

6.5.1 ‘Acknowledging change’

The data demonstrate that, similar to aspects of Willoughby and Keating’s (1991) and Keady and Nolan’s (2003) theories, informal carers now move to acknowledge that the changes noted are signifiers of something abnormal. However, at this point it still may not be clear that dementia is what is wrong. The informal carer is piecing together the indicators of differences, moving to the stronger acknowledgement of change, which advances the sense of ‘Unsettled place’. As one participant described it:

“... you can see changes happening but you have to accept them. You can’t just brush them under the carpet and say it’s not happening.” (CFM08)

Informal carers illustrate that this can occur in a number of ways. Firstly, encountering the person with dementia outside a normal interaction situation may enable an informal carer to recognise how serious thing now are. Secondly, activities familiar to the person with dementia may suddenly no longer be possible. Finally, the individual context of the person with dementia's life is important. For example, a person may still be in employment or hold a position of responsibility in family, social or occupational life. In such a case, change may be acknowledged faster because the impact of decreasing ability to self-care or perform required tasks can have a more noticeable effect. Two particular examples from the data vividly support this:

"... when they [parents] were on holidays they went to get, went to pay in the hotel and he [participant's father with dementia] got panicky because he had the money, and then he had forgotten then how to use the bankers card, he was getting very confused over it ..." (CFM01)

"... he [participant's husband] started to go out in the back garden bring out the hoover instead of bringing out the lawnmower ..." (CFM06)

As the indicators of change start to mount up, the informal carer may turn to medical sources of explanation. Where there is some acknowledgement that something is not right, depression is one example of how changes are accounted for in some participants' narratives:

"I thought it was the effect of the depression for so long on his [participant's husband's] brain and that was my main thought. I wouldn't have considered Alzheimer's - dementia at that stage." (CFM14)

This was supported by one of the allied health care participants who was also an informal carer:

"... at first I thought he [participant's husband with dementia] was suffering from depression, and I would go to the GP and explain that (name of husband) was very unwell ..." (AHPDO6).

The data suggest that when one explanation is insufficient, other alternatives are sought, for example:

"... he [participant's husband] was forgetting things, but we put it all down to eyesight, his eyesight was fading, so it had to be cataract." (CFM07)

Explanations employed are those which are potentially actionable, that is they are amenable to amelioration, treatment (medical) and/or cure. This can lead the informal carer from doctor to doctor and specialty to specialty.

Overall, the data demonstrate that 'acknowledging change' is related to: the nature of the relationship of the informal carer and the person with dementia, the visibility of the indicators and the speed of progressive deterioration or change. This indicator of 'piecing the story together' can occur in advance of or alongside the second indicator, 'forming and sharing suspicions' of dementia.

6.5.2 'Forming and sharing suspicions'

Over time suspicions add up to the potential presence of dementia. In some instances this arises from the informal carer or it may be that someone else starts to mention things that they have noted. Forming suspicions of dementia can therefore be stimulated by indicators or consequences of advancing dementia. The level of intrusion is increasing and dementia is making its presence felt in particular and undeniable ways. The sense of 'Unsettled place' continues to increase for informal carers, who in this study observed:

"... so I formed the opinion then that she [participant's wife with dementia] knew that she was lacking some element of memory ... that was when I got the first suspicion ..." (CFM03)

"... and I knew as it was getting worse I knew it had to be something like Alzheimer's, you know..." (CFM10)

Having formed suspicions of dementia an informal carer will usually take some action. In the first instance, and similar to actions described by Perry (2002), this can be sharing their suspicions. In most cases telling the story is a deliberate act. The time has come to open up to another person. Sometimes informal carers may share suspicions with the person with dementia, unless they decide to actively protect them and shoulder the suspicions on their own. However, the first port of call is frequently someone within the family, as illustrated by this participant:

"So it was at that stage then, well over all this stage I was saying it to my brother and sister ..." (CFM17)

A medical professional or a trusted confidante may also be identified as the best person to tell the story to. It is at this time that the informal carer and the person with dementia may begin the health care journey, but not yet on the specialist dementia care route. For example, a number of participants began by consulting with their general practitioner:

"... it was really when she [participant's mother] started doing things like not knowing how to turn on the TV, or she would look at the fridge and not know what it was, then I began to think that it was a bit more. It was then I brought her to the GP."(CFM05)

Having shared suspicions, it is often the case that the informal carer may find that others may have already formed similar or the same suspicions. This was the case for CFM03 when he opened up to his children:

"And then I discussed it with my daughters, and they were saying; "well, we noticed something like that too", so that's how it happened." (CFM03)

Finding that others have suspicions, about the possible presence of dementia, may be a source of solace or despair to the informal carer who may have been hoping, even now, to have their suspicions disconfirmed. Thus, sharing the suspicion of dementia is a significant event, as it signifies advancement in terms of 'Unsettled place'. It confirms that a growing schism from one's known place is occurring that is beyond the control of the informal carer and signals the approaching of the final property of 'Unsettled place', which is 'apprehending dementia'.

6.6 'Apprehending dementia'

Dementia is apprehended when its manifestations become so overt as to be unavoidable and/or when a preliminary diagnosis is given.[44] The apprehending of dementia legitimates earlier suspicions. The perception of dementia in terms of a disease can benefit carers, who now have a named entity that is responsible for the changes identified. As a disease, dementia is an entity about which there is something to know that exists apart from or outside the person with dementia (Gubrium, 1986). As such, a preliminary diagnosis of dementia can offer a temporary respite from a sense of 'Unsettled place'. It accounts for what is occurring and can be named and blamed. However, dementia is soon recognised as posing an increasingly unsettling influence. This is because finding out what accounts for the changes, rather than being the solution, exacerbates the sense of 'Unsettled place'. The indictors of 'apprehending dementia' are 'realisation' and 'resistance'.

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[44] In most cases, the informal carer and person with dementia do not encounter specialist services until 'Threatened place', the next component of the theory.

6.6.1 'Realisation'

The realisation of dementia is not a homogeneous experience for all. For some informal carers, it comes prior to receiving a diagnosis where the affects are overt or where a carer has previous experience. In such cases, an informal carer is reasonably sure that dementia is now the issue. Informal carer participants described their experience of realisation in different ways:

"By the time it kicked in and it dawned on everybody, the realisation kicked in ..." (CFM11)

"No I went to that meeting and we had the discussion and it dawned on me straight away that's [dementia] what's wrong with mum." (CFM17)

For others, realisation may require an external stimulus, for example an authoritative source or confirmation with medical examination. This was the case for the following participant whose GP forced her to face the presence of dementia for what she explained was her own good:

"... sharp words from my doctor; "accept it (participant's name)", right, and I said; "right, ok, I got to accept it, I know it's gonna happen"." (CFM07)

Other informal carers identify an explicit moment of realisation that is akin to a light bulb clicking on:

"And with that the penny dropped with me." (CFM11)

"And then I realised that's it." (CFM16)

This has been reported previously by informal carers of persons with dementia (Betts Adams, 2006). However, in this study, the moment of realisation is for informal carers a stimulus for a simultaneous realisation of a definite sense of 'Unsettled place', which is linked to the impact of dementia and the potential need for actions to sustain place moving forward (Chapter 8). Regardless of the mechanism of realisation, in this theory the data suggest that this is not synonymous with acceptance of dementia. This contrasts with previous research, in which realisation of dementia is followed by gradual acceptance (Lindgren, 1993). However in 'Unsettled place', one can know about the presence of dementia but not necessarily accept it. Despite this, the informal carer must acknowledge what is occurring because the status quo is irreparably damaged. This is supported by participants' narratives, which demonstrate that life is not and will not be the same as it was:

"You realise from that moment on that your life stops as you had previously known it. And you take a turn." (CFM18)

"... there is nothing can be done for the situation, it's [dementia] going to get steadily worse." (CFM07)

While the realisation of dementia suggests a no going back, the data make it apparent that realisation can co-exist in tension with resistance to dementia.

6.6.2 'Resistance'

For many informal carers, there is an ongoing tension between knowing that dementia is present but resisting it. Resistance at this point in 'Sustaining Place' could be linked to an early form of protection. In some cases this may relate to self-protection for the informal carer and in others protection of the person with dementia. Importantly, resistance as a form of protection cannot be maintained. As an action, it is also ineffective when considered alongside the potential efficacy of the forms of protective actions taken in the third component of the theory, 'Sustaining our place' (Chapter 8). The data suggest a number ways in which resistance can be manifested and reasons why resistance to dementia can occur. For example, resisting dementia-related connotations and resistance to the reactions of others to the presence of dementia, as illustrated by this participant:

"... that he [participant's father with dementia] would be laughed at or looked upon as being strange." (CFM01)

The lack of a definitive test for dementia, which is a clinical diagnosis, can also support resisting dementia because there cannot be 100% proof of its presence. Informal carers in this study also demonstrate that resistance can occur even when an informal carer has previous experience of dementia. In such a case, there may be in-depth dementia knowledge and skills, but the thought of this happening again can be too much to contemplate. In some cases, the informal carer tries to sustain a hope that what is happening is not happening. It is easier to sustain resistance where the person with dementia is unaware or hides the presence of dementia. Where the realisation of dementia is interpreted as horrifying, resistance can be a coping mechanism - I don't want this therefore I resist acceptance. Informal carers' narratives are particularly poignant in this regard, as exemplified in the following extracts:

"Yes, and I knew, but what I knew, didn't want to come out." (CFM07)

"... until I got around the shock of it, I was shut down." (CFM09)

Resistance may also be linked to a perception of unfairness and/or an expectation that at a certain stage in life, one has earned the right to a preferred place. In such instances, informal carers portray that they should not have to encounter dementia:

"I just didn't want the whole thing around us at all." (CFM02)

Finally, resistance can occur where the person with dementia is perceived to be above such a thing because they are highly educated or have occupied a position of authority, as illustrated here:

"Because how could this, so well, fit, young man, who had worked at a very responsible job all his life, and being very intelligent, possibly have "a thing like that [dementia]", it couldn't be ... worked his way up and all this kind of thing, and then he's entitled to his retirement and then all of a sudden he's struck with this thing." (CFM11)

Participants' narratives suggest that the function of resistance is that it can be temporarily sustaining, as it protects the informal carer for a while. This is because resistance can offer refuge from the sense of 'Unsettled place'. However, resistance can only sustain an individual for so long - after this time it becomes an impediment to what is happening and only delays the process of onward movement to the next component of 'Sustaining Place'. Ultimately resistance is a cul-de-sac, in that it does not fruitfully contribute to lessening the perception of 'Unsettled place', nor does it enable the identification of strategies to address it. At this point, the problem of 'Living on the fringes' is increasingly acute and informal carers are akin to what Becker (1997: 120), writing in relation to chronic illness, describes as liminal people whose "sense of order" has been disrupted.

6.7 Transitioning to 'Threatened place'

Apprehending dementia is a critical moment in 'Sustaining Place' because it signals the transition to the second component of the theory 'Threatened place'. 'Unsettled place' once encountered is the only component of the theory that cannot be revisited. Informal carers spoke about how they recognised that their lives and those of persons with dementia are irrevocably altered and the inevitability of consequent change. Dementia-related events involving other people, organisations and society, now start to be mentally logged in time and in some instances in this study in written diary format. While serving as a source of comparison in terms of the progression of dementia, the logging of dementia-related events becomes integral to the overall process of ‘Sustaining Place’. Logged events are a stimulus to action or are used as evidence when evaluating the outcomes of actions taken to sustain place. The socially constructed meanings of dementia (Chapter 2) may now begin to affect the carer’s interpretation of what is happening. The realisation of the inability to resolve the encountered differences is accompanied by sensitivity to inter-relational experiences. This continues into the next component of the theory, when others’ reactions to the presence of dementia are increasingly encountered. The outcome of ‘Unsettled place’ may result in a perception of being and/or being perceived as different. As encounters with the indicators of ‘Threatened place’ occur and begin to grow in intensity or number, often coinciding with progressions in dementia, the transition from ‘Unsettled place’ to ‘Threatened place’ is completed. In the next chapter, this second component of ‘Sustaining Place’ will be presented.

Chapter 7 'Threatened Place'

7.1 Introduction to 'Threatened place'

This chapter presents the second component of 'Sustaining Place', which is 'Threatened place'. Here the impacts of dementia-related change and informal carers' and others' reactions to its presence, associations and consequences have two outcomes. Firstly, there is a disruption to the informal carer's sense of belongingness, purpose and directionality. Secondly, the acute awareness of the problem of 'Living on the fringes' (Chapter 1, Section 1.3) culminates in a recognition of the necessity to take action. This occurs due to a sense of separation or disconnection from a familiar way of being in, and relating to, the known life-world and potentially a resultant crisis in terms of the informal carer's biographical narrative.[45] Where 'place' is restricted, denied and eventually threatened, there is a fracture in the taken for granted and habituated sense of order that generally pervades everyday life. As informal carers increasingly confront disturbances to their place, and that of the person with dementia, the world as previously experienced cannot be taken for granted. Instead, informal carers question their altered relationships with multiple aspects of their lives. This is compounded as the components of 'Threatened place' are encountered and informal carers are increasingly thrust into inter-relational encounters in unknown aspects of their life-worlds (for example health and social care systems). In addition, the altered inter-relational experiences of the person with dementia are witnessed. While it could appear that 'Threatened place' is happening 'to' a passive informal carer, the data suggest that informal carers are actively involved in socially constructing meaning in the context of inter-relational encounters. Thus, 'Threatened place' is not an inherently intra-psychic process relating to self. Instead, it is self in relation to others that is at issue because dementia associated meanings and experiences are constructed within the social spaces between and among people, organisations and society. Most threats to place are consequently extrinsic to the informal carer and extrinsic to the informal carer-person with dementia dyad. 'Threatened place' is comprised of the following properties: 'whittling to core', 'becoming a lesser person', 'negative health and social care contacting' and 'no idea whatsoever' (Figure 7.1).

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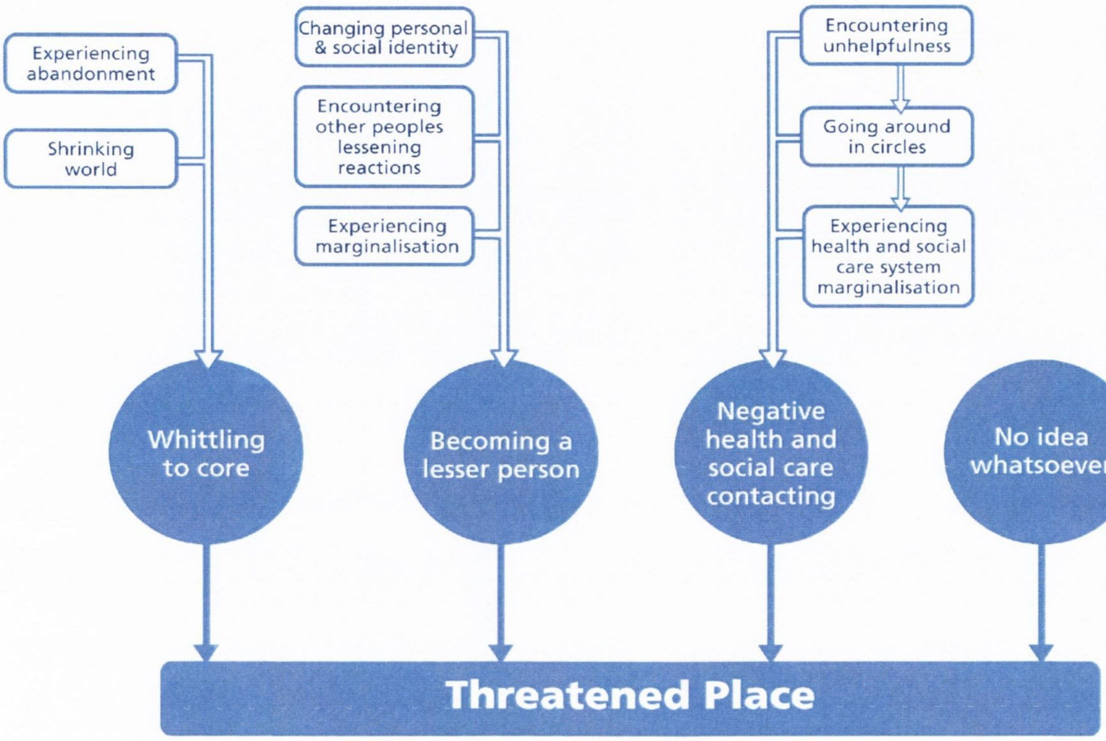
[45] The term narrative is used here in the manner explicated by Hess (2003), who is in turn informed by Sally Gadow's perspective on relational narrative. According to Hess (2003: 141), narrative is "an epistemological mode for the configuration of the self where the socio-cultural and personal levels of narrative intermingle".

Figure 7.1 Threatened Place



7.2 'Whittling to core'

Once dementia is apprehended (Chapter 6, Section 6.6), there is an increasing propensity for changes to the nature and experience of interactions with family, friends, occupational and other social contacts. As dementia progresses and its manifestations necessitate an increasing amount of informal carer time, opportunities for social contact usually decrease. In some instances, relational withdrawal can be on the part of the informal carer so as to cope with or effectively manage the caring role. In the main however, participants suggest that withdrawal of and/or abandonment by family, friends, colleagues or support networks is a stark reality experienced by many informal carers and persons with dementia. Consequently, opportunities for human contact reduce as people contact progressively whittles away, as described by these participants:

"They [friends] kinda melted away ..." [CFM05]

"... they [friends] used to call in after mass and have a cup of tea and have a chat but that just stopped..." [CFM17]

Often a core set of supports and contacts remain, which can buffer the situation somewhat. Sometimes those persons that continue to support the informal carer and person with dementia may not be those that might have been forecasted to do so. This illustrates people's very individual reaction to dementia, its manifestations and those whose lives are touched by it. The indicators of 'whittling to core' are: 'experiencing abandonment' and 'shrinking world'.

7.2.1 'Experiencing abandonment'

In many instances, the pre-existence of good relationships with others creates an expectation by the informal carer that he/she will have some support from family, close friends and/or co-workers. The nature of the desired support varies from moral support and recognition to instrumental assistance. Where this expectation is not fulfilled, informal carers refer to 'experiencing abandonment' and feeling very let down, not just for themselves but also for the person with dementia. This can result in strong emotional reactions, including: disbelief, anger, sadness and/or despair. When speaking of this, informal carers referred to two groupings. Firstly, and most significantly, participants highlighted abandonment by family, for example:

"... you just leave her sitting on the chair and someone will come. I'll ring social services and someone will take her ..." [CFM12 paraphrasing a family member's reaction to her mother with dementia's need for care]

"I remember that it was discussed that they [sisters] would put a little bed into mammy's room and they would come [and stay] and that did not materialise ..." [CFM15]

The feeling of being let down is in some cases particularly poignant when family members are perceived by informal carers to think badly of them. The data suggest this can occur in relation to: matters of allocation of caring responsibility, property, inheritance or family difficulties, in part or whole due to reactions to the impact of dementia and/or demands of dementia-related needs. Where this happens, it can result in difficulty and sometimes catastrophic breakdown of family relationships, as described by the following informal carer:

"they're [other family members] dragging me into court now ... I feel angry for them, I feel anger over them, the way they treated me, more so than what my mother got ... [Alzheimer's disease]" [CFM10]

The experiences of some of the experienced allied health and social participants in this study support this point. This extract is from a social care provider who works closely with primary informal carers in a specialist dementia care setting:

"... the one thing that I do find with Alzheimer's disease, it can either make or break a family, it can unite a family ... or it can ... split a family where ... other members of the family just criticise or try to undermine everything that person is trying to achieve." [AHPDO4]

The second form of abandonment recounted by informal carers is that of friends, colleagues and other social contacts. Participants' narratives describing such experiences are heavily emotion laden and portray a sense of being let down and disappointment, as shown here:

"... I was hurt, I was very, very hurt by the fact that his [participant's husband with dementia] colleagues didn't come to visit ..." [CFM02]

"... and I think if his [participant's husband with dementia] friends that knew him before he got it [dementia] had continued to talk to him as if he hadn't got it, I think it would have helped." [CFM20]

The experience of abandonment is recognised in both mental health and informal dementia care research and has been linked to feelings of resentment (Lindgren, 1993; Champlin, 2009; Hayes, Boylestein and Zimmerman, 2009). When engaging in meaning-making in terms of experiencing abandonment, many informal carers in this study offer explanations or rationales for others' actions. Participants referred to: ignorance, fear of dementia, dementia-related stigma and people being at a loss and not knowing what to do or being afraid of saying or doing the wrong thing:

"And then people, ignorance is coming back into my mind because like myself they don't know." [CFM15]

"... as time has gone on she [participant's mother with dementia] has stopped going to friends and people have stopped coming to her and I think that is part of, you know the stigma attached to it, you know?" [CFM04]

"I think people have probably become a little afraid of socialising with us because they are not quite sure of the situation [dementia]." [CFM13]

For one participant in particular, the potential for abandonment was not surprising. It mirrored her perception of society as it currently operates. This is illustrated in the following fieldnote memo:

"She [CFM16] felt that people pulled back from her. They stopped calling ... she thought this was because she could not meet them half way, as well as because of the presence of dementia. She also related this aspect of the experience to changes in society and a diminution of a visiting culture. People don't generally call around anymore – the phenomenon of the 'rambling house' has disappeared. They [other people] are too busy." [FNM CFM16]

7.2.2 'Shrinking world'

Isolation can be linked to what Doka (2004) refers to as secondary losses associated with informal dementia caring. These include loss of social roles, work roles and interpersonal relationships. A finding of isolation is not uncommon within informal caring research (Willoughby and Keating, 1991; Wuest, King Ericson and Noerager Stern, 1994; Gates, 2000; Galvin, Todres and Richardson, 2005; Betts Adams, 2006; Papastavrou et al, 2007; Andren and Elmstahl, 2008; Champlin, 2009). The data in this study support isolation in multiple ways. However, rather than the focus being on role loss, it is on the way in which loss of the ability or opportunity to engage in relational experiences relates to the experience and meaning of 'Threatened place'. The informal carer becomes acutely aware that as social interaction is lessening and increasingly more difficult to sustain, he/she is becoming progressively more isolated. The data demonstrate that this is mainly due to withdrawal by others or because the inherently progressive disability associated with dementia, complicates social interaction for the person with dementia and by association the informal carer. Participants stated:

"... I don't go out an awful lot ..." [CFM06]

"My other problem is I have so many stories I want to tell. And they [family] don't want to hear really ... they don't want to be listening about mammy." [CFM17]

The resultant impact on human contact and freedom, particularly social contact and in some cases work, are evident. Similar to other research (Wilson, 1989a; Svanstrom and Dahlberg, 2004), informal carers referred to feeling tied down and restricted. The concept of a shrinking world was particularly illustrated by one participant in this study (CFM18). Interestingly, Duggan et al (2008) also use this term in an article exploring the impact of dementia on the outdoor world of persons with early dementia. Herein though, the term refers to shrinkage in broader terms than the physical world and refers to the world of the informal carer as well as that of the person with dementia. The simplest things, previously not consciously needing a great deal of consideration, for example going to the shop, meeting friends or even having the freedom to choose whether or not to engage in social interactions, now require advance planning or have to be withdrawn from. In consequence, aspects of an informal carer's life-world begin to diminish in tandem with the restrictions encountered in opportunities for engagement and withdrawal by others. Skaff and Pearlin (1992: 657) refer to this as "constriction in the scope of [informal carers'] lives". Informal carers vividly illustrate shrinkage, or condensing, of their social spaces, which culminates in a perception of being cut off from some or all aspects of their pre-caring social worlds, as these extracts demonstrate:

"... not feeling I have freedom is difficult ..." [CFM05]

"All of the things [singing in a choir and being in a friendship group] as simple as they might be, I miss them more than anything." [CFM14]

"One's world is shrinking." [CFM18]

While it cannot be assumed that all informal carers of persons with dementia experience 'whittling to core', the majority of those in this study refer to this phenomenon. Informal carers indicate that abandonment and isolation are two of the most difficult components of 'Threatened place'. These are compounded by the second property of this sub-component of the theory, 'becoming a lesser person'.

7.3 'Becoming a lesser person'

The data suggest that informal carers and persons with dementia are inseparable from the social and cultural worlds that comprise their experiences and structure meanings and actions. This is because people emerge through social interaction, not as fixed but as constituted and reconstituted through the various discursive practices in which they participate (Davies and Harre, 1990). Social exchanges are the contexts within which people interact (Carpentier et al, 2008). As such, it is within the nexus of various social exchanges that informal carers appreciate who they are and how they and the person with dementia are regarded by others. Many informal carers in this study considered that a diagnosis of dementia almost implied that they and the person with dementia are regarded as lesser persons, compared to the time prior to the presence of dementia. The indicators of 'becoming a lesser person' are: 'changing personal and social identity', 'encountering other people's lessening reactions' and 'experiencing marginalisation".

7.3.1 'Changing personal and social identity'

An informal carer's and person with dementia's social identities undergo significant changes, which are interpreted by informal carers as important contributors to 'Threatened place'. Firstly, the identities that signify the inter-relationship between the person with dementia and informal carer are perceived to change. The data suggest that as dementia progresses, the person with dementia remains a person. However, there is loss of aspects of his/her identity prior to dementia, which alters the informal carer-person with dementia dyad. This is demonstrated in the following exemplar from a participant:

"… you've lost other friends and you lost your dearest friend [person with dementia]. They've gone to a place you can't follow and you're left with this shell that you just have to care for, and it is difficult, very, very difficult." [AHPD02 who was both an informal and formal carer]

Secondly, informal carers refer to changes to their roles (social, occupational etc), or the ways in which roles are operationalised, that complicate their ability to participate and inter-relate with the person with dementia and others. This is an important indicator of 'becoming a lesser person' because the ability to engage in such activities is considered central to who one is by informal carers. The way in which social identities (that of the informal carer and person with dementia) are conceptualised as changing with dementia progression, lead informal carers to speak of the multiple losses they experience. This is poignantly illustrated here:

"I don't do anything except care for him [participant's husband with dementia], I do nothing at all, I don't go. I haven't been out after certainly eight o'clock at night in the past five years … Yeah that is what I am, that's what I do, right. That is my role in life from the time I wake up to the time I go to bed …" [CFM07]

"Well all that had to change [the way in which this participant had lived]. No longer could I go out and leave [wife with dementia]. No longer could [participant's wife] go out … And so on, the list [of losses] is virtually endless. You realise from that moment on [diagnosis] that your life stops as you had previously known it. And you take a turn … And you have to accept it." [CFM18]

The conceptualisation of the social identities of the informal carer and person with dementia in the eyes of others, and the impact on how they are then related to, are also a focus of informal carers' concern. Thus, this indicator and the next, 'encountering other people's lessening reactions', concur with Mac Rae's (2008) position that rather than being internally constituted, identity from an interactionist perspective is a social product, created and preserved in the context of social interaction.

7.3.2 'Encountering other people's lessening reactions'

Informal carers can be subject to difficult and sometimes negative familial and social interactions that exacerbate the sense of being unequal or different to others. Such relational experiences can infringe the citizenship of the informal carer and person with dementia. They can also increase the likelihood of an informal carer needing to engage in actions designed to counter or resist exclusion, abandonment and discrimination. One participant recalled:

"Our town would be quite small ... the amount of people, which was really tough at the time, that criticised us for putting mam in a nursing home, you wouldn't believe it" [CFM19]

Allied health and social care participants' narratives concur with this, as these extracts exemplify:

"It was dreadful for her [an informal carer] because she said if she went to hang out clothes on the line, her neighbour next door would go in, in case she had to speak to her." [AHPDO6]

"They [persons with dementia] were now a lesser person [after diagnosis] and treated with lesser respect or their intellectual abilities were not seen, a disability was seen." [AHPDO9]

When dementia is relatively inconspicuous and the manifestations amenable to covering and/or passing (Goffman, 1963), being publicly present may not be such an issue. The data suggest that informal carers usually continue to try to maintain familiar social activities, as shown here:

"... well we [participant and his wife with dementia] often walk down the [place name] pier and we'll meet people that we knew playing cards ..." [CFM03]

"I generally, I don't avoid things, I mean if she [participant's mother with dementia] talks, she talks ..." [CFM05]

However, where a diagnosis becomes known or knowable, a different set of experiences may be encountered. For example, Doka (2004) highlights that informal carers can experience humiliation and embarrassment associated with social outbursts and alterations of inhibitions in the person with dementia. Significantly, informal carers can also be hurt by the reactions of others when this occurs, as these participants explained:

"... he [participant's husband with dementia] was constantly going out there telling them [children] off ... so mothers would come charging in then, "how dare you let your husband speak to my child like that ... he should be put away."" [CFM07]

"And one time now he [participant's husband] used to go down, left out the shopping [list] to get milk and bread. He used to love to go and I used to write it [shopping] down and give him the money and the man in the shop asked me not to send him down. I don't know what happened. That hurt me." [CFM16]

Where unusual or atypical social behaviours occur, the visibility of the informal carer and person with dementia is increased and they then become subject to the regard of others. Being subject to the gaze and reactions of the outside world is a particularly difficult facet of 'Threatened place', described here by a daughter carer:

"... I mean sometimes depending on what she might say to somebody, I might be embarrassed, so I just kind of smile." [CFM05]

The threat or potential for becoming visible often implies a necessity for informal carers to remain on high alert when in the company of other people or to take action to lessen the potential for this, as will be demonstrated in the next component of the process (Chapter 8). However, where the manifestations of dementia are not immediately obvious, some informal carers may not be believed by others. Often these could be those persons the informal carer confides in who may not see the changes or do not want to see them. This can exacerbate the informal carer's feelings of negative regard and rejection, compounding the experience of increasing social isolation described previously. The following participants explained:

"It actually frustrates me that people, you know, doubt me [in relation to the presence of dementia], you know what I mean? And were saying to me that I was going a bit overboard ..." [CFM04]

"I had nobody because they [participant's husband's family] wouldn't believe that [name of husband] was diagnosed with Alzheimer's ... I used to be told "Don't be upset with [name of husband], don't go home and upset [name of husband]"." [CFM09]

Participants' narratives support the hypothesis that fitting in appears to be an important component of having a recognised place:

"I think the society needs to categorise people. They can't handle it if you don't fit a category ..." [CFM11]

However, when dementia is an aspect of people's lives, conforming to social expectations becomes progressively more difficult. As one deviates from expected or established ways of being and relating, difficulties can arise. Shotter (1989) concurs and highlights the expectation of social accountability, which is the moral expectation that people must communicate in socially expected ways to sustain status. Reactions to informal carers, while similar, are different to those faced by persons with dementia. The data make it clear that people, organisations and society often don't seem to know how to handle interactions with informal carers and persons with dementia. Consequently, dehumanising responses can arise. The data suggest this may be due to lack of sensitivity, skills or understanding of dementia. Informal carers also describe instances where they observe the person with dementia being treated in an upsetting or unacceptable manner by the public, their acquaintances or health and social professionals.[46] Examples from the data include: being talked over, ignored, looked at or left in silent isolation with no purposeful interaction or activity:

"They [people] stand back because it [dementia] is too heavy type of thing you know, that's the way I would look at it." [CFM11]

"They talk to me but the way they talk to him [participant's husband with dementia], brings the attention and it becomes all of a sudden, I feel we've become like a circus." [CFM07]

"And I suppose people look at this person [referring to persons with dementia in general] and say, "God what's wrong with her?" You know, I think that's where this stigma thing comes from." [CFM15]

Interestingly, where positive reactions and inter-relations with other people are experienced, this can diminish other more negative interactions and are interpreted by informal carers as contributing to a sense of 'Sustained place' (Chapter 9, Section 9.2). For example, CFM08 referred to the supportive effect of such interactions. However, in 'Threatened place', it is the

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[46] The contribution of health and social care personnel and systems to 'Threatened place' is primarily considered in Section 7.4.

negative reactions of other people that are of concern. This is because they are quite often experienced and interpreted by informal carers as implying diminished status. This relates to the final indicator of 'becoming a lesser person', 'experiencing marginalisation'.

7.3.3 'Experiencing marginalisation'

The person with dementia and the informal carer can encounter experiences that suggest they are being regarded as somehow outside what is considered by people and society as 'normal'. It is as if being regarded as such implies that they are then not necessarily amenable to accepted conventions for interacting with others. This was observed in a number of interviews and documented in the fieldnote extract below:

"CFM19 commented on the way in which ... there is a feeling of lack of support, being an outsider, different and not cared for ... What you want is a sense of being part of what is going on around you not to be regarded as different." [FNM CFM19]

Allied health and social care professionals were cognisant of this also, as this participant explains:

"It [dementia] would have been very much seen in the community as sort of, as a psychiatric illness and that person was now known, they were now quite a different person to the person they were..." [AHPDO9]

Informal carers relate marginalisation to a number of issues. It is perceived that when a diagnosis has been applied to persons with dementia, they become subject to stereotyping in terms of what this implies for who they are, what they can do and their position in society. Informal carers speak of also being marginalised by being associated with the implications of these stereotypes, as well as the degree to which they are able to participate in society. The attributions applied to those with dementia are related by informal carers to commonly held perceptions of dementia. The data suggest these are socially constructed and frequently inherited from a previous generation. In some cases, informal carers acknowledge having held these same inherited social understandings before encountering dementia, but having developed a different, more informed, understanding following experience of the informal caring role. The data suggest that inherited understandings of dementia do not appear to have a basis in medically constructed dementia discourse (Chapter 2, Section 2.3.3). Instead, society is perceived to understand dementia as a complicated word, which is constructed from a lay perspective through negative associations, labels and images that can evoke fear (for example, that persons with dementia can be violent or that dementia is an age related occurrence). The informal carers in this study used the following terminology when referring to lay understandings of dementia and persons with dementia:

"... the wanderers, walkers ..." [CFM01 referring to how persons with dementia can be viewed]

"they [people from participants youth] called it [dementia] doting ... and well, that's insanity" [CFM03]

"What came to mind was, this only happens to old people ..." [CFM07]

Allied health and social care professionals in this study also referred to such understandings:

"... the never ending funeral or you know the language used in the past to convey the kind of terror of dementia." [AHPDO7]

The final sense in which marginalisation is referred to is the impact of the cost of dementia care on some informal carers' sense of place. Services and supports that enable sustenance of place are reported as *'costing a fortune' [CFM01]*. Sometimes a home might have to be sold or a service forgone, either of which can compound marginalisation, as these participants demonstrate:

"I take grave exception to houses having to be sold that took forty years to build up a home ... I find that devastating, because nobody really builds it up for that and we have all paid our tax. We've paid whatever dues were due to the state and in view of the way that money is being wasted so greatly, I think it's dreadful that people have to, family homes have to be sold ..." [CFM02]

"We don't go out very often to anything but we never go out at night 'cos if we go out at night it is fifty quid [to pay someone to be with her mother who has dementia] for a night." [CFM12]

7.4 'Negative health and social care contacting'

Negative instances of contact with formal health and social care services are some of the most powerful threats to place encountered by informal carers. While some may be lucky enough to gain access to skilled and understanding professionals quickly, for others this is not the case. Negative contacting is a significant threat to place, particularly when formal care contexts are perceived as offering support and assistance to make a qualitative difference to the life of the person with dementia and the informal carer. Informal carers hopes are realistic in that they do not seek the impossible - a cure. There is however an initial trust that the formal systems contain the informational, technical, medical and caring expertise of the best of what can be done. Where 'negative health and social care contacting' is encountered, this trust is quickly dissipated. Negative health and social care encounters can lead to resentment of these systems, which are then conceptualised as inhospitable and in some cases inhumane. Some informal carers can feel alienated, trying to gain access to those that have the right expertise but with no clear route to reach this destination. The indicators of 'negative health and social care contacting' are: 'encountering unhelpfulness', 'going around in circles' and 'experiencing health and social care system marginalisation'.

7.4.1 'Encountering unhelpfulness'

Most informal carers do not have a great deal, if any, previous experience of dementia and/or the formal care systems. In consequence, they frequently do not know the possibilities that exist to assist them and the person with dementia. It is concerning that informal carers speak of experiencing unhelpfulness and encountering professionals who should know but do not know. Some informal carers also refer to experiencing therapeutic nihilism, such as non-referral to specialist services. The data suggests that both of the above compound threats to place. Therapeutic nihilism in relation to interventions to assist those with dementia has been reported in Irish research with general practitioners (Cahill et al, 2006). When 'encountering unhelpfulness', trial and error can then sometimes be the only route available to the informal carer seeking help and access to those with expertise in the formal health and social care systems. This is however tiring and difficult to accommodate within the nexus of the many ongoing changes to their lives and those of persons with dementia. The arduous and frustrating aspects of these experiences are evident in the following participant extracts:

"…even I rang like, I'm trying to think of the names of the places I rang, um our local social welfare officer and you know even then there was [unhelpfulness], I didn't ring back like, I didn't … I wasn't getting anything that was going to be really any use to me." [CFM04]

"… he [doctor] just said "Well he [participant's husband with dementia] has Alzheimer's", and then that was it. Medication, [name of drug], mental medication, no assessment after that in the four years." [CFM06]

Previous research supports this aspect of 'negative health and social care contacting'. For example, a significant European survey of dementia carers recently identified lack of satisfaction with the level of information provided at diagnosis, with four out of five informal carers considering the level of aged care for their country to be poor (Georges et al, 2008). Morton (2003) refers to her anger in relation to the insensitivity of some medical professions encountered in her role as carer for her husband, while a report by the Nuffield Council on Bioethics (2009) refers to informal carer accounts of being treated with suspicion by professionals. Nolan, Grant and Keady (1996) and Keady and Nolan (2003) further highlight findings of informal carers concerns being discounted, goals being blocked and the compounding affect on their perceptions of working alone. In contrast, participants in Zabalegui et al's (2008) research were positive about particular professionals but heavily criticised the formal care system itself. Similarly, Carpentier et al (2008) identifies the inappropriateness of available services, particularly to those persons in the early stages of dementia. Of concern in 'Threatened place', is that 'encountering unhelpfulness' may lead to a frustrating cycle of 'going around in circles' where carers speak of being passed through formal systems with little discussion or perceived rationale.

7.4.2 'Going around in circles'

Illustrations of 'going around in circles' imply a sense of almost dizziness in circumstances where informal carers feel that they are being rushed through one nodal system connection point to the next. This is worsened where an informal carer perceives that they are being pressured. For example, where a person with dementia has been offered a service but the informal carer is told that this is time limited due to resources. The informal carer has to locate the next service before the time limit runs out. Informal carers can then feel that their time must be devoted to finding the next suitable service or doctor and that they have to do so without the requisite knowledge or expertise. In so doing, informal carers are not focusing on the person with dementia or their own needs, as shown here:

"... but we were warned when we went in that this is two weeks and two weeks only, so we were still under stress or strain ... when he [participant's father with dementia] was in respite for two weeks they kept pressuring us, reminding us all the time ... "look out for a nursing home"." [CFM01]

"She [mother] was in hospital 7,8,9,10,11 times. In for four days, out for a day ... you have to go through the same rigmarole again. It's just totally crazy, total waste of time and so frustrating, I can't understand it." [CFM19]

In such circumstances, a sense of place is very difficult to maintain as the ground is constantly shifting under the informal carer's feet. Frustration grows, particularly where available services are complex, insufficient to meet people's needs, inflexible or geographically dependent. For many, the resultant frustration is all the worse as delays, hold-ups, disconnections and/or gaps in the systems are encountered. This can result in informal carers having to take responsibility for connections between services instead of being connected to them, as these informal carer participants illustrate:

"I told her [nurse,] all I need a home help for was [to] come in at 8 o'clock or half eight in the morning, to lets say half nine 'til that bus comes, that way I won't be late for work ... [nurse] said "we don't work before nine o'clock or half nine and we don't work after half three or so"..." [CFM10]

"... there is no central place where you can ... ring and say "can you give me all this information for these things?" ... you've got to track around the different organisations yourself, whereas if you don't know them, that's very difficult ... they don't all connect." [CFM05]

This aspect of 'negative health and social care contacting' is not just recognised by informal carers. The existence of difficulties in terms of co-ordination and communication between services and healthcare sectors and their impacts on service efficiency and care are recognised by European leaders in the field (Vernooij-Dassen et al, 2005). In this component of the theory, 'encountering unhelpfulness' and 'going around in circles' can lead to a perception of being marginalised and demeaned within formal care systems, greatly exacerbating the experience of 'Threatened place'.

7.4.3 'Experiencing health and social care system marginalisation'

While section 7.3.3 explicated societal marginalisation, marginalisation is also experienced within the health and social care systems. Marginalising encounters with health and social care systems and personnel have been highlighted before in dementia research (Willoughby and Keating, 1991; Werner, Goldstein and Buchbinder, 2010) and in relation to older persons' experiences of the Irish health system (McGlone and Fitzgerald, 2005). Marginalisation in terms of health and social care systems is experienced by informal carers in this study as a third form of abandonment, in addition to the two forms previously identified (Section 7.2.1). The nature of such marginalisation is almost palpable in the following extracts:

"Oh [vehemently], we had to do everything on our own. No help! No assistance, there was absolutely, there was nothing!" [CFM01]

"We felt as though we were abandoned and that we didn't know where to go next ... you just manage as long as you can ..." [CFM13]

The potential for abandonment and/or marginalisation is also recognised by those within the healthcare system who work within the dementia specialist field. These professionals generally possess the advanced knowledge, skills and experience that informal carers seek. However, they may be difficult to access unless informal carers encounter others who enable access through specialist referral mechanisms. As noted by one such participant:

"They [informal carers and persons with dementia] could have been four to five years on their own, not knowing that the Alzheimer's society existed, not knowing that the services were in place for them ... one of the questions I always asked was "were you not informed of the Alzheimer's Society and the work that they do?" and nine times out of ten the answer was "no"!" [AHPDO4]

This is a pivotal issue because it will be shown that "positive interacting" with health and social care professionals is an important indicator of 'Sustained self' (Chapter 9, Section 9.2.4). A number of factors are identified that lead to perceptions of system marginalisation. The conditions encountered within formal systems are frequently identified as illustrations of abandonment. This is the case where, for example, an informal carer perceives that the level and quality of care is insufficient to meet the carer's needs and those of the person with dementia. Other examples include: the feeling of being set adrift within formal systems, not being consulted during assessments or when decisions are made (even though an informal carer knows his/her own abilities and needs and those of the person with dementia if he/she can't communicate them) and not being provided with information, as evidenced in these extracts:

"... for ten minutes we left the ward for the staff to look after him [participant's father with dementia] and change the linen, they went off and left him and he got out of his bed and walked down the hospital and when I came on the scene, all I could hear was laughter, from staff members..." [CFM01]

"I ended up in tears one day, 4,5,6 hours waiting to see a doctor ... he dismissed me as if I wasn't even there ... And it was very frustrating." [CFM15]

"I was given nothing [no information or guidance] by the consultant. I really would, looking back, take exception to that!" [CFM20]

Some informal carers and professionals refer to the consequences of professional dementia-related stigma. This is attributed to negative attitudes, stereotyping, inherited understandings of dementia and a dearth of specialist knowledge and skills, as exemplified by this daughter carer:

"I often found my father sitting in the room, just pushed in, he's sitting in a chair ... just looking at a wall ..." [CFM01],

In support of this issue, a health professional participant stated:

"...it is one [thing] that annoys me, the attitude of health care professionals to dementia sufferers ... the day before you have the diagnosis, you are Miss or Mr, and you get the diagnosis and suddenly you are 'Dearie', what is that?... It is dehumanising, and to have that dehumanising language and behaviour used by professionals is appalling." [AHPDO9]

Similar experiences are reported elsewhere in Alzheimer's research and attributed to aspects of what is termed structural stigma (Werner, Goldstein and Buchbinder, 2010). In 'Sustaining Place', where it is also perceived that the healthcare system disregards the person with dementia or informal carer because of diagnosis or age, informal carers experience frustration and anger, as these extracts convey:

"... to me like something's broken so it's [person with dementia] old so don't bother trying to fix it or don't bother trying to repair, just leave them there and just get on with it ..." [CFM12]

"The group called NICE, you know them? ... They are saying no point in giving it [named drug] to the person who is only mildly Alzheimer, it won't do any good ... they were thinking "how much is this going to cost?"" [CFM18]

"... the GP said "What do you expect at your age?" [AHPDO2 who was both an informal and formal carer]

Resultant marginalisation can lead to a perception that if something other than dementia was the case, maybe a different approach to, or more, care would be given. Informal carers in such instances can conclude that dementia comes lower down in the pecking order than other diagnoses, as the wife of the person with dementia interviewed in this study pointed out in the following interview extract:

"I find that when we go to see the GP, we usually go every 3 months to get a repeat prescription, and I sort of feel that if we go with little problems say, [they] aren't really taken all that seriously because we're, I suppose, because we're old anyway [and] because [participant's husband] has Alzheimer's. I just feel that he doesn't get the same attention." [CFM13]

Researcher question to CFM13 and PWD1: Do you feel then that the issue is clouded by the diagnosis, the other diagnosis, the Alzheimer's?

"Well I hope it's not but I have that feeling." [CFM13]

These extracts also illustrate that in the case of informal carers and persons with dementia who are older, some carers highlight their belief that they are subject to system marginalisation on the basis of both age and diagnosis. This was referred to by one health professional in this study as a *"double whammy" [AHPDO7].*

7.5 'No idea whatsoever'

In the meleis of experiences and constructed meanings outlined above, coupled with the progressive difficulties of living with the effects of dementia, informal carers cannot be sure of what dementia may imply for: their lives, the life of the person with dementia and their sense of connection to and belongingness in their life-worlds. For those with no experience of dementia, this is a particular concern that advances the perception of 'Threatened place'. Not knowing is further compounded as the sense of alienation from the surrounding world grows. As aspects of the previously known life-world are turned upside down, an informal carer can experience a sense of ontological uncertainty or as Burkitt (2008: 170) terms it "ontological insecurity". This is illustrated in these informal carer interview extracts:

"Well it never rang a bell with me, what it was like ... I had no idea whatsoever ..." [CFM08]

"Your place is nearly gone. Near enough." [CFM17]

"It was totally an unknown minefield." [CFM18]

According to one writer, people who experience a life disruption can experience a period of limbo before they restore a sense of order (Becker, 1997). However, a sense of order may not be easily restored in the presence of dementia. This finding is similar to that of Champlin (2009: 1529) who found that in "being there", informal carers of people with serious mental ill-health recognised that a permanent solution to the experience was not possible. Informal carers may continue to not be able to fulfil or adapt to social, occupational or other expectations and roles. Their lives can be unpredictable and they may need to respond at a moments notice to the needs of the person or the demands of the disability. Informal carers feel they are consequently at once in but not in the world. This may be observed by others who, as illustrated above, may then treat the informal carer and person with dementia differently. Therefore, the data suggest that people, organisations and society may not be able to accommodate and/or tolerate difference. However, in light of the progressive nature of dementia, the informal carer's focus is not the regaining of order. It moves instead to the sustenance of 'a' place, which may imply adjustment to living with difference and disorder.

7.6 Transitioning to 'Sustaining our place'

As 'Threatened place' reaches a crescendo, the recognition of differences in multiple domains of the informal carer's life-world is complete. This signifies the beginning of the transition to the next component of the process, as actions directed towards sustenance of the place of the informal carer and that of the person with dementia now become a central concern. Throughout 'Threatened place', informal carers engage in an evaluative process wherein the indexing of dementia related events (Chapter 6, Section 6.7) continues, serving as a mechanism to actively evaluate threats to place. Thus, informal carers proceed to 'Sustaining our place' (Chapter 8), only if they consider 'Threatened place' significant enough to warrant action. The parameters within which such a decision is made are individual. The protective, defensive and inter-relational actions that are encompassed within 'Sustaining our place' are consequently invoked when an acute awareness of an unacceptable intensity of 'Threatened place' moves an informal carer onward. Ideologies of 'normalcy' are called into question as the carer considers whether or not he/she and the person with dementia are regarded by people, organisations and society as: belonging, worthy of positive regard and accepted for who they are and the roles that they can now play. In such cases, the person is extricated from predictability, custom and previous ways of seeing life (Becker, 1997) and forced to address the "the exigent life circumstances created …" (Kleinman, 1988: xiii). Depending on the outcome of their deliberations, informal carers can experience a sense of social loss and/or devaluation, which they perceive extends to the person with dementia. It is as if there are shifts in social symmetry, directed away from the informal carer and person with dementia. In reaction, the informal carer moves to address these shifts by transitioning to engage in the third component of the theory, ‘Sustaining our place’, which will be explained in the next chapter.

Chapter 8 'Sustaining Our Place'

"They say that time changes things, but you actually have to change them yourself"

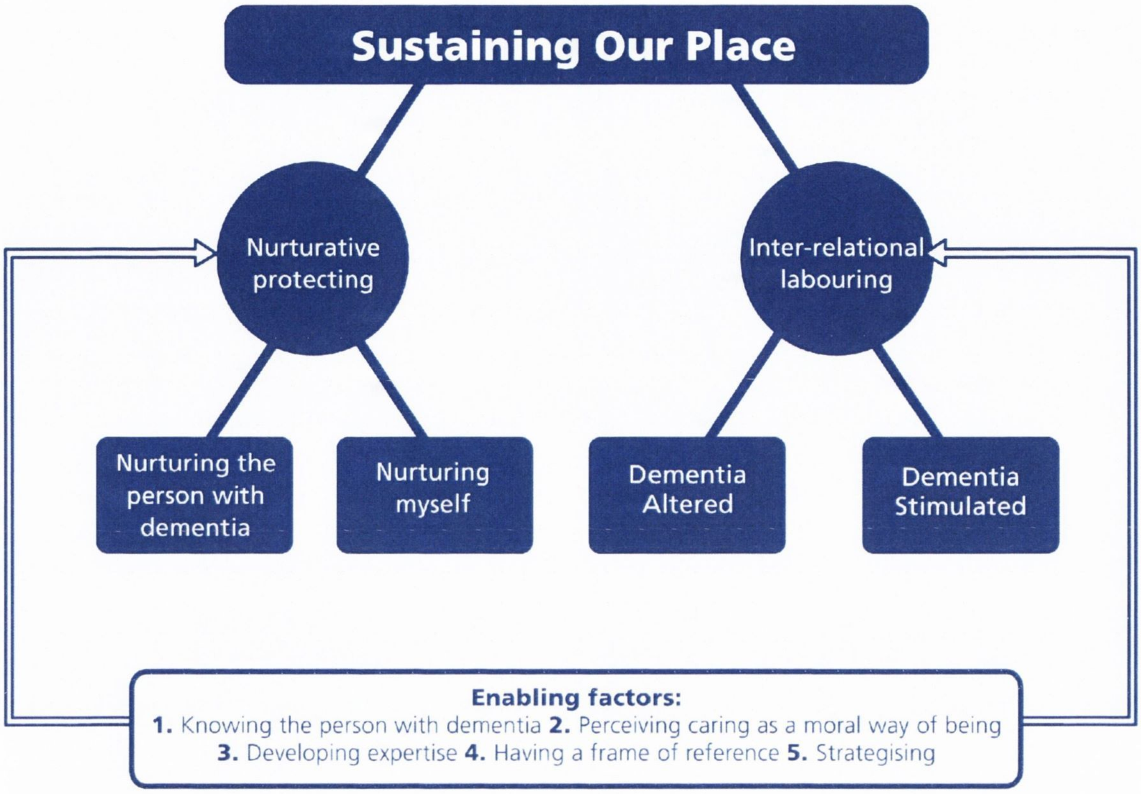
- Andy Warhol (1928-1987)

8.1 Introduction to 'Sustaining our place'

This chapter explains the third component of the theory, which is called 'Sustaining our place'. In 'Sustaining our place', the informal carer engages in a number of specific activities to address the problem of 'Living on the fringes' (Chapter 1, Section 1.3). The informal carer therefore moves from experiencing and interpreting 'Threatened place' to doing something about it. Interestingly, the act of engaging in efforts to sustain place contributes to the affirmation of having a place as informal carers are operating from a particular position in doing so. This contrasts with previous research, such as that conducted by Svanstrom and Dahlberg (2004: 677), in which informal carers and persons with dementia are suggested to "become strangers in their own world", resulting in lives lacking coherence and meaning and a consequent orientation towards day to day coping. Instead, in 'Sustaining our place', the right to place is exerted and acted upon (whether consciously or unconsciously). Depending on the most pressing need identified by the informal carer, the most imminent threats to place may be prioritised for attention.

This component of the theory consequently consists of various protective, defensive and inter-relational actions directed towards the resolution of the problem of 'Living on the fringes'. In engaging in 'Sustaining our place', informal carers' aim is to simultaneously sustain their and the person with dementia's places. However, where dementia is progressing, the person with dementia's abilities may no longer support participation in particular contexts. If this happens, or where threats to place are perceived as overwhelming, informal carers may choose to limit interaction to those contexts within which place can be sustained. 'Sustaining our place' (Figure 8.1) is comprised of: 'nurturative protecting' (which is informal carer and person with dementia-centred) and 'inter-relational labouring' (which is encountered-other centred). Informal carers' actions within these sub-categories are facilitated by five specific enabling factors that strengthen an individual carer's actions to sustain place (Figure 8.1).

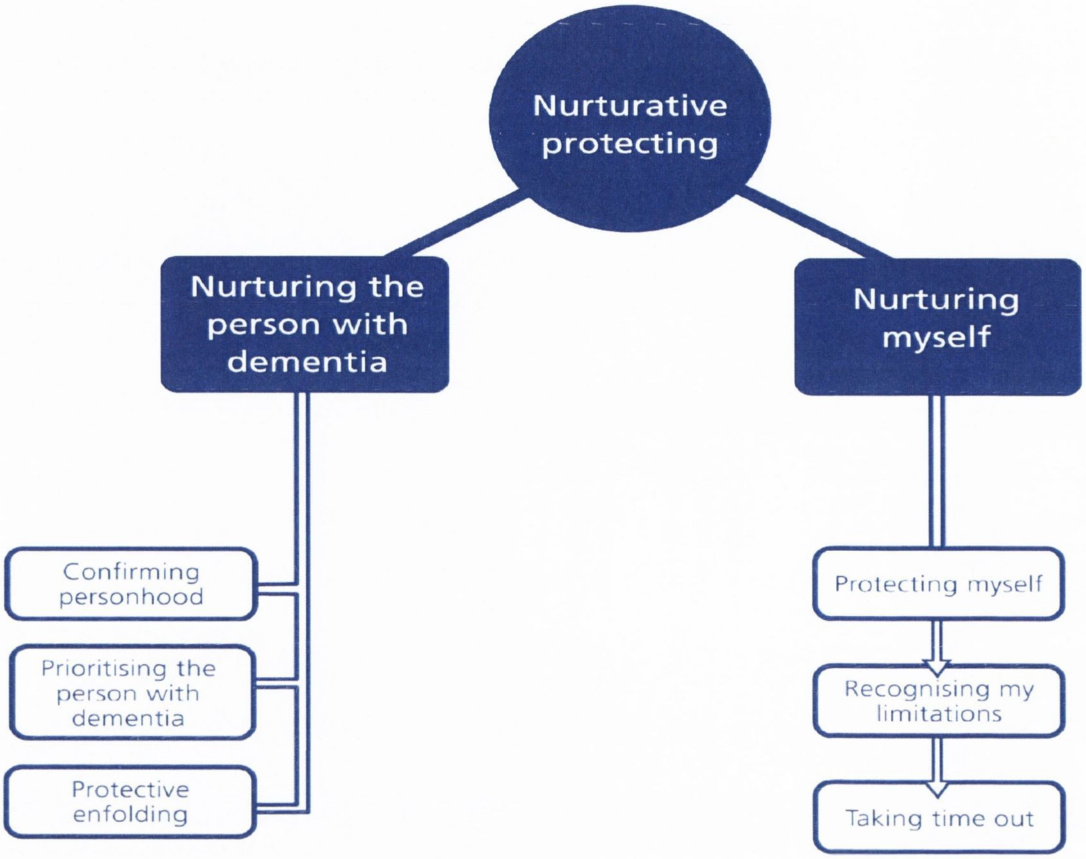
Figure 8.1 'Sustaining Our Place'



8.2 'Nurturative protecting'

Definitions of nurture refer to terms such as: to sustain, to foster development or to cultivate (Gilmour, 2003). Similarly, 'nurturative protecting' is employed by informal carers in this study to simultaneously sustain individual distinctness (their own and that of the person with dementia) and to ensure the respect and recognition of a specific and valued place-in-the-world for both. Gates (2000) identifies 'nurturant giving' as a constituent of her structural definition of informal care, in relation to the promotion of quality of life for those in receipt of care. Hellstrom, Nolan and Lundh (2007) also refer to nurture in relation to contexts that sustain couplehood between spouses in dementia. These references to nurture/nurturing, contrast to the use of the term here. This is because in 'nurturative protecting', nurturance is conceptualised as one component of sustaining the place of both the informal carer and person with dementia in relation to other people, organisations and society. The related actions that informal carers engage in can thus be conceptualised as: person with dementia centred, informal carer centred or both. Previous research (Chapter 3, Section 3.5) does not appear to conceptualise informal carer actions in this manner, or they are subsumed into the overall informal caring trajectory. 'Nurturative protecting' is presented with reference to its properties, which are: 'nurturing the person with dementia' and 'nurturing myself' (Figure 8.2).

Figure 8.2 'Nurturative protecting'



8.2.1 'Nurturing the person with dementia'

'Nurturing the person with dementia' encompasses the nurturing actions that primarily involve the informal carer-person with dementia dyad and not the wider contexts in which threatened place is encountered. According to Kitwood and Bredin (1992), people need to be respected and have their status as a person recognised. This is supported by Richard Taylor (2007: 149) who has dementia and writes: "I do know that I continue to need to be recognised as a Thou, to have my personhood recognised. Please understand I am still here". This implies having a recognised and valued place. In this theory, actions associated with 'nurturing the person with dementia' are directed towards the immediate upholding of his/her social status or as one daughter carer explained:

"I mean as you say maintaining her [mother with dementia]." [CFM15]

The indicators of nurturing the person with dementia are: 'confirming personhood', 'prioritising the person with dementia' and 'protective enfolding'.

8.2.1.1 'Confirming personhood'

Informal carers engage in three activities designed to strengthen and sustain the personhood of the person with dementia. Firstly, in recounting the biography of the person, he/she is confirmed as a person of worth with a specific life-history, situated in webs of relationships with other people, organisations and society. Both the informal carer narrative data and my interview fieldnotes support this action:

"... my father was a man that was, he was very caring, gentle individual, never could lift his hand to anybody or voice to anybody, never could do it." [CFM01]

"... at the end of the interview, she [CFM16] told me of her childhood and that of her mother [with Alzheimer's disease] ... and traced their lives for me over time. She seemed to be reviewing the biography of all those whose lives had been touched by this dementia and she was doing this to help me to understand who they were as persons, their humanity and their situatedness in the fabric of time, personal history and family." [FNM CFM16]

The understanding of personhood herein differs somewhat to Kitwood's (1997) perspective in which personhood is bestowed or given to a person.[47] It also differs from Perry (2002) who depicts how wives explain who their husbands were before dementia as a means to maintain the presence of their spouse, and Caron and Bowers (2003) who describe how informal carers work towards preserving the person with dementia sense of self and value. In this study, 'confirming personhood' aims for more. This action is directed towards ensuring that the person with dementia sustains a social right to and occupies a valued and particular place in relation to the informal carer and the life-worlds in which they are situated. It is as if this right should not be dependent on others granting or bestowing it on them – it is a right of citizenship arising out of one's being a person.

Two other activities are also used to confirm personhood: the preservation of dignity and accompanying the person with dementia. To informal carers, dignity is a fundamental right and a duty to uphold. Actions to preserve the dignity of the person with dementia are consequently of central concern, as they signify direct respect for the person's personhood. Linked to this, is accompanying the person with dementia. While this can be in a physical sense, in 'Sustaining our place' it refers to a metaphorical sense of accompaniment and the maintenance of fidelity. Thus, being with and beside the person with dementia is perceived as recognition of place, as recounted by this participant:

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[47] Kitwood's (1997) perspective on personhood is explained in Chapter 2 (Section 2.3.5).

"... I want to be there, I want to be there for mammy. ... she [participant's mother with dementia] is still mam. I want to see her and I want to see her oftener because she knows me and likes to communicate with me ..." [CFM15],

and noted in the following fieldnote extract:

"She [CFM14] makes her wishes for her husband known in terms of arguing for his appearance to be maintained ... an illustration of an action taken on behalf of her husband to maintain his place, as a person deserving of respect and the maintenance of dignity... ensuring that his appearance is always as she perceives he would have wished it to be is so important to her. It is one way in which her husband's standing and individuality can be illustrated to others and confirmed." [FNM CFM14]

8.2.1.2 'Prioritising the person with dementia'

To confirm the place of and the person with dementia, informal carers also identify the need to focus on and prioritise the person in terms of sustaining actions. Informal carers stated:

"...I ask God to keep me fairly good to look after him [participant's husband with dementia] – for as long [as I can]." [CFM14]

"... we go nowhere on our own, and everything that we do in our lives now is done for her [participant's mother with dementia] and it's done around her." [CFM12]

An important aspect of this is to try to continue to engage in familiar activities and ways of doing things with the person. In so doing, the intent is to sustain the usual and comforting aspects of the person with dementia's place. It is also so others will continue to relate to the whole PERSON with dementia and not the person with DEMENTIA, consistent with writers such as Kitwood (1997), Brooker (2007) and Christie and Cunningham (2009). Examples of this from the data included trying to engage in activities that are routine and familiar, the ordinary things that all people do, as these participants explained:

"...we [participant and her husband with dementia] went on holidays, we went into town, did our shopping, all up to Christmas, you know. [CFM06]

"Done things we always did, yeah." [CFM09]

"... we did everything as if life was normal." [AHPDO2 who was both an informal and formal carer]

In prioritising their loved one, informal carers may be at risk of subjugating their own needs and wants. However, the need to focus on the person with dementia is generally perceived by informal carers as their responsibility and consequently not always a matter of choice, as this husband of a wife with dementia pointed out:

"What else can you do?"[CFM08]

8.2.1.3 'Protective enfolding'

In this component of the theory, 'protective enfolding' centres on explicit actions designed to protect the person with dementia from external threats to place (Chapter 7). Protection is referred to in other informal dementia care research in terms of physical protection of the person with dementia, for example in Wuest, King Ericson and Noerager Stern (1994) and Perry (2002). However, the data in this study suggest that these actions protect not just from an embodied or a sense of self perspective, but also from an inter-relational perspective. This was clearly illustrated in a number of informal carers' narratives and interactions with me as researcher:

"Oh you are protecting him [participant's husband with dementia] all the time ..." [CFM16]

"[our pre-interview conversation] gave her a chance to test my commitment to the area [of dementia] and my qualifications for my stated research purpose. To me, it demonstrated her commitment to her husband and served as a type of protective mechanism on behalf of her husband (and herself) – supporting the emergent findings relating to protecting." [FNM CFM14]

Various forms of protective action can be employed in 'protective enfolding', with the choice of action influenced by context and interaction related considerations. For example, an informal carer may choose either protective silence, where the presence or impact of dementia is not made known or protective disclosure, where an informal carer may reveal the presence of dementia and its impacts. Similarly, advance telling involves informing those one is about to come into contact with about the dementia with the intent of eliciting understanding and sensitivity. Examples of data supporting these actions include:

Protective silence: "… just the way things were done, you just didn't go out and talk about it." [CFM12]

Protective disclosure: "I have never hidden it [dementia]. From the beginning I told everyone because I was hoping they would understand if [participant's husband] acted a bit funny." [CFM20]

Advance telling: "If I am going to go and visit someone, I explain to them the situation and [they say] "that doesn't matter, we won't mind"." [CFM08]

Remaining on constant alert is another pro-active protective action used when in interaction with others. Here, an informal carer remains on guard for instances of potential threats to the place of the person with dementia and as dementia progresses instances of actual threats to this person's place (Chapter 7). Where this occurs, the level of 'protective enfolding' may be increased temporarily, as if on a sliding scale or continuum. For example, where threats to the person with dementia's place are difficult to defend against, an informal carer may begin to delimit the contexts engaged in with the person. Choosing social spaces is thus an action to ensure that a person with dementia is exposed to contexts in which it is possible to sustain his/her place and by default in which retained abilities can be maximised. Informal carer participants described the following in this regard:

"I'm kinda on high alert sometimes because people [encountered when out and about] do look kind of odd." [CFM05]

"She [participant's mother with dementia] is a very social person, she likes company and likes people so it's very important, [we] tried to continue that for her but within comfortable space." [CFM04]

Perry and O'Connor (2002) identified strategising encounters and protection by supporting retained competencies, in contrast to emphasising losses, as means by which spouses act to preserve selfhood in persons with dementia (Chapter 3, Section 3.5.1). Bowers (1987) also conceptualised 'protective caregiving' in this manner, identifying it as the central aspect of the informal caring role. Caron and Bowers (2003) and Farran et al (2004) also refer to engaging in caregiving with this intent, while Willoughby and Keating (1991) identify controlling interactions with others as central aspects of the informal caring role. These while similar to in another sense contrast with this aspect of 'nurturing the person with dementia', as the intent of informal carers in this study is broader than preserving personhood. As previously illustrated, it relates instead to sustaining place and the right to this place in the context of encounters with other people, organisations and society. However, Perry and O'Connor (2002) do note that the preservation of personhood can benefit the carer as well as the person with dementia. This finding buttresses the contention of 'Sustaining our place' that informal carers act simultaneously to benefit themselves and persons with dementia. In terms of 'nurturative protecting', there is however an ongoing tension for informal carers between 'nurturing the person with dementia' and 'nurturing myself'. This is supported by Barnes (2006) and Barnes and Brannelly (2008), who found that informal dementia carers accepted responsibility for caring out of a relational ontology, while trying to balance caring responsibilities with responsibility to themselves. Vikstrom et al (2008) have also identified the need to balance time for oneself and caring for the person with dementia as a particular dilemma in informal dementia care, but not in the context of 'Sustaining Place' conceptualised herein.

8.2.2 'Nurturing myself'

The informal carer is the instrument through which 'Sustaining our place' is addressed. If the capacity to engage in the related activities breaks down, 'Sustaining our place' may become increasingly difficult. This may occur for a number of reasons:

- firstly, where an informal carer focuses only on the person with dementia, neglecting his/her own place,
- secondly, where the demands of caring become so intense that the carer is forced to focus on the immediate needs arising within the informal carer-person with dementia dyad and
- thirdly, where encounters with the sub-categories and indicators of 'Threatened place' (Chapter 7) are perceived to be overwhelming.

The need to 'nurture myself' is therefore important if the overall process is to continue over time. The indicators of 'nurturing myself' are: 'protecting myself', 'recognising my limitations' and 'taking time out'.

8.2.2.1 'Protecting myself'

Becoming a primary carer for a person with dementia almost always necessitates dramatic change to multiple aspects of a person's life. To enable the informal carer to sustain the caregiving role, the need to engage in 'protecting myself' is recognised and where possible acted on by carers. Informal carers in this study spoke about: being determined, drawing on different strengths, maintaining hope and managing their emotions (including resisting guilt) as examples of protective mechanisms designed to enable them to sustain their place:

"We got to a very late stage [of dementia] but that was determination on my part and I think other people are the same." [AHPDO6 who was both an informal and formal carer]

"My strength in my family is our religious belief and we, it got us through ..." [CFM01]

"... and all the time they [the hospital] were doing tests, of course [we thought] magic is going to happen." [CFM07]

"It [how people treat the carer] makes you a little bit sad and maybe supersensitive that people can hurt you. Maybe I am getting a bit tougher about it now. I was a bit weepy about it at one stage. I've come to terms with it ..." [CFM16]

Informal carers also choose or reject roles and interactional spaces. For example, one informal carer in this study spoke of what is/is not her role. Others referred to: role reversal, juggling roles, multi-tasking or trying to combine roles, or of having to concentrate on the informal caring role, while relinquishing roles or opportunities for social and/or occupational interaction, as the following extracts exemplify:

"... I think that the GP or consultant should tell the patient that they can't drive ... as far as I'm concerned that's part of their duty." [CFM02]

"So I had to take on [the household roles] or getting someone to look after these things, which I never had to do before." [CFM20]

"And you struggle with your present roles [work] because you keep feeling you should give them up ... that [work] is the place that I am me." [CFM17]

"That [caring] is my role in life and is from the moment I wake up to the time I go to bed. .... This is the job to do and everything must revolve around that." [CFM07]

The issues of managing competing roles, role captivity and the related consequences have also been identified in other dementia research (Chapter 3, Sections 3.5.2 and 3.5.3). 'Nurturing myself' evokes strong emotional reactions in informal carers, in particular guilt, but is viewed as central to the protection of oneself. This action also recognises the personal limits to the ability to engage in informal care.

8.2.2.2 'Recognising my limitations'

An informal carer will usually continue to engage in 'Sustaining our place' for as long as possible but may develop a growing understanding that a point may come where a choice, in most cases temporary, between prioritising 'I' (myself) over 'you' (person with dementia) or 'us' may have to be made. In support of this, participants explained:

"I'm realising more every day that ... a time will come when I just can't handle it [the informal caring role] ..." [CFM03]

"... I couldn't continue ... and look after mum, you know what I mean, because her needs became, you know, too great." [CFM04]

The existence of limitations to the ability to engage in informal care have been highlighted by others (Wilson, 1989a; Willoughby and Keating, 1991; Post, 2000b; Butcher, Holkup and Buckwalter, 2001), as have informal carers attempts to balance responsibilities for those in receipt of care and responsibilities to care for themselves (Barnes and Brannelly, 2008). Herein, the act of 'recognising my limitations' seems to suggest a threshold effect. This infers that there is an individual tipping point at which informal carers acknowledge that their abilities to simultaneously sustain their places and those of persons with dementia are compromised. One daughter carer expressed this in the following way:

"... I was so close to mammy that I was taking this so much on board and ...if I had a disconnection from it [caring and its consequences] a little bit I might have been able to handle it better... Yes it consumed me." [CFM15]

Where informal carers need to temporarily prioritise themselves, although it may appear that the person with dementia is sidelined, the data suggest this is not the case. Instead, informal carers may be indirectly nurturing and protecting the person with dementia by creating a space to engage in 'nurturing myself'. By 'nurturing myself' an informal carer may enhance the ability to continue to 'Sustain our place' over a more prolonged period of time. As such, 'recognising my limitations' will usually lead to focused and explicit actions to facilitate time to focus on oneself.

8.2.2.3 'Taking time out'

Actions relating to 'taking time out' may be either proactive, to prevent reaching or exceeding individual caring capacity, or immediate where the need for time out is pressing. Self-affirming is one action employed by informal carers to this end. This is similar to recounting biography, which was referred to in the context of 'confirming personhood' (8.2.1.1), but here it refers to the confirmation of the informal carer as a person. Scott (2009) refers to the use of similar retrospective narratives as a means to re-establish order in one's life and create meaning by those who experience illness. However, this is not the case here. Instead, informal carers recount their life stories/biographies to those who show willingness to listen as a way to convey and confirm their place and/or to demonstrate how it has changed, as illustrated in these fieldnotes:

"Before we started [the interview] she [CFM15] opened a black leather folder and pulled out some single sheets of paper with handwritten notations ... journal entries dated ... written when caring for her mother. She wanted me to have a snapshot of what she had been through." [FNM CFM15]

"He [husband of a woman with dementia] told me how important it was to be listened to and to have opportunities to tell his story." [FNM CFM18]

Informal carers may also seek ways to remove themselves temporarily from direct caring involvement. Where this happens, an informal carer will make contingency plans for the future, if and when time out becomes necessary, or arrange cover for their caring role where the need for time out is immediate. However, supportive others are not a given and where unavailable the sustenance of place can be particularly difficult for an individual carer. Those informal carers who are well supported, may involve family members, friends and acquaintances to enable them to sustain their place and that of the person with dementia. For example, others may be engaged to: share caring responsibility, as a source of social support, to provide temporary respite and/or as a social connection for the person with dementia. Informal carer participants recalled:

"Well my own friends were very good ... I would meet them in town ...some from the family would stay in [and take care of participant's husband]..." [CFM02]

"Yes, so I rang her [mother with dementia's] sister from the country who came up ... and stayed with her for three days and I just went off on a break ..." [CFM05]

Taking time out may also relate to accepting or accessing formal supports, where these are available. Often the informal carer may have been trying to go it alone but having recognised the limitations to this, formal help becomes an option. Examples of the different forms of help accessed in this study included: home help, respite, day care and in some cases residential care. Informal carer participants captured the need for such assistance in the following ways:

"When things got tough, I had to go and look for help." [CFM06]

"But sometimes we [participant and her husband with dementia] need time apart." [CFM13]

"No I would go in every day [to visit her mother in respite]. But if I was gone away for a few days, fine ... It recharges your batteries. So I used to really look forward to her coming home and I would be really excited." [CFM15]

'Taking time out' is however only an effective action where an informal carer is confident in the appropriateness, quality and safety of the alternative care provided, as shown here:

"...I'm just completely secure in the fact that she's looked after and for five days ... she has somebody with her, you know as company ... which I think is stimulating for her and I think will keep her well for longer." [CFM04]

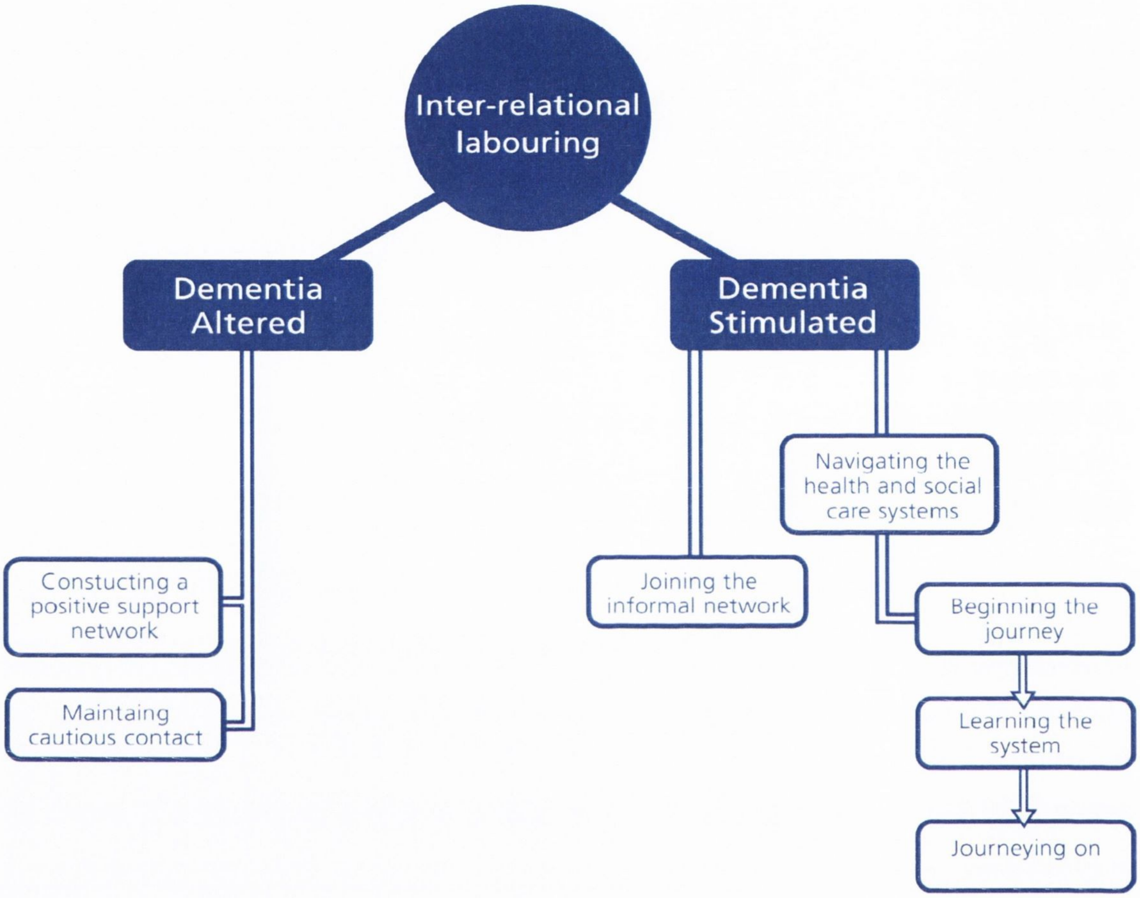
Similar to other informal dementia care research (Wilson, 1989b; Aneshensel et al, 1995; Zarit and Gaugler, 2006), where a person with dementia moves to residential care, informal carers do not see this as the termination of their caring role. Instead, the nature of caring may change and for some is just as involved.

8.3 'Inter-relational labouring'

Many of the actions in 'Sustaining our place' are stimulated by encounters, or lack thereof, with others, within which the informal carer must mediate the differences experienced within multiple aspects of his/her life-world. These bring the informal carer and person with dementia into contact with other people, organisations and wider society and so inter-relational interactions are simultaneously the catalyst for and nexus within which actions to sustain place occur. This sub-category has been named inter-relational labouring because informal carers frequently interpret 'Sustaining our place' interactions with others as a form of work. In contrast to 'nurturative protecting', the focus in 'inter-relational labouring' moves outward beyond the immediate informal carer-person with dementia dyad to other people, organisations and society.

‘Inter-relational labouring’ has two properties: ‘dementia altered inter-relational labouring’ and ‘dementia stimulated inter-relational labouring’ (Figure 8.3).

Figure 8.3 ‘Inter-relational labouring’



8.3.1 ‘Dementia altered inter-relational labouring’

‘Dementia altered inter-relational labouring’ encompasses actions that informal carers engage in, to sustain their and the person with dementia’s places when in the presence of people they know, for example: family, friends, neighbours or acquaintances. The indicators of this property of ‘interelational labouring’ are: ‘constructing a positive support network’ and ‘maintaining cautious contact’.

8.3.1.1 ‘Constructing a positive support network’

Informal carers highlight that not all people known to them will necessarily be supportive of place, particularly as the impact and consequences of dementia grow with its progression. Avoidance of those who are either unsupportive or directly threaten place can be perceived as necessary because their presence may militate against the sustenance of place. The construction of a positive support network is considered to be of central importance and informal carers will usually begin to categorise those known to them as supportive and helpful or not supportive and helpful, as illustrated here:

Question: But you didn't speak to them [close family members] about the dementia [how difficult things were]?
"No! Depending on who the people were in categories ..." [CFM15]

Informal carers may test others' commitment and/or ability to be supportive and helpful as a filtering mechanism.

Example of categorising as unhelpful:
"I suppose for me, I kept thinking she'll [friend] get it [how hard caring is] someday. She'll get it and she never got it... And you get to a stage then that you don't go to those people. And that is very sad because you loose a lot of people then." [CFM19]

Examples of categorising as helpful:
"... there was one aunt who was very supportive from day one ..." [CFM05]

"I find he [son] is wonderful ... So he would be good to talk to and he is very good with [participant's husband with dementia]" [CFM14]

The situating of dementia in terms of family is central to this process. In many cases, families function as a primary means of support to place. For some however, the family structure may already be divided or where the consequences of 'Living on the fringes' cause family tension or upset, family may become problematic. Becker (1997: 107), writing in relation to illness, concurs that families "may both aggravate disruption and create continuity". Consequently, informal carers tend to categorise their families or individuals within the family as supportive or un-supportive. Those persons seen to pose a direct threat to the place of the informal carer or the person with dementia may be avoided. Informal carer participants expressed this in the following ways:

"I got to a stage when I was afraid to even tell them [family] that I was putting her [participant's mother with dementia] into respite, you know? ... hard enough my mother having this without the family giving me more grief." [CFM10]

"... there is a couple of other family members, I won't even go there." [CFM19]

Alternatively, informal carers tend to work with and maintain close contact with family members perceived as partners in care or supportive of place, as these participants demonstrated:

"We spend a lot of time with family, our own family and actually my husband's family. They're great with her [participant's mother with dementia] and they include her in everything." [CFM04]

"... mam [participant's mother with dementia] is 80 in August and ... they're [family] organising a big party for her ..." [CFM12]

In some instances a categorisation may change over time, illustrating the continuous nature of both categorisation and commitment testing. If someone who is not initially categorised as supportive later becomes supportive, they may move from the unhelpful/unsupportive to helpful/supportive category or the opposite may occur.

8.3.1.2 'Maintaining cautious contact'

The need to maintain contact with people, organisations and society is central to the upholding of place. The ongoing renewal of informal carer hope has similarly been linked to connecting with others by Duggleby et al (2009). However, awareness that other people may be supportive or not supportive of sustaining place (Section 8.3.1.1), infers that the nature of such contact is often cautious, particularly when in the presence of the person with dementia.[48] The following exemplars illustrate the tensions inherent in this action:

"And I felt once or twice that I spoke to them about it and I felt maybe they were a little hurt that I was speaking my mind. Then I sort of stayed quiet." [CFM15]

"It all passed off lovely [wedding]. It was a woeful strain." [CFM16]

Informal carers may often employ a number of tactical cautious mechanisms to sustain contact with social contexts. While some of these have been highlighted in previous research (Morton, 2003; Betts Adams, 2006), their use here is to enable the sustenance of place and not to deny the presence of dementia. Examples of informal carer actions used to this end include minimising

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[48] Cautious contacting here refers to maintaining rather than reducing contact to sustain place, which is referred to in Section 8.2.1.3.

visibility and hiding reality. The following extract vividly illustrates the measures this informal carer wife engaged in:

"He's [participant's husband with dementia] pushing his trolley [in the supermarket]... and all of a sudden the trolley goes off that bloody way, and people are looking as much as [to say] "is he drunk?", but I discovered when I put his dark glasses on, people suddenly say, "ah, the poor man can't see"." [CFM07]

Another informal carer (also now a formal carer) explained:

"From a personal point of view, [name of participant's husband with dementia] was diagnosed, say he was fifty-three years of age. The only people that knew was our family and I wouldn't say we even told close friends, simply because of his age ... they [persons with dementia] have a standing in the society in the community [implication is that this is compromised in the presence of dementia]." [AHPDO6]

Cautious contacting is also used to protect the family and the place of the person with dementia within it. In relation to the person with dementia, related actions aim to maintain the person's position within the family and with others (Goffman, 1959). For example, some informal carers (spouses and children) indicated that they either did not tell their own children about the dementia until absolutely necessary or minimised its impact. Similarly, Betts Adams (2006) also found that spouses employed a limited disclosure of the realities of everyday living to adult children. However, in this study, not telling appears to preserve the place of the informal carer, that of the person with dementia and may also protect the place of children. This occurs particularly where the impact of dementia is considered a risk to the preservation of the ideology of the family and individuals' places within it. Informal carers described this in the following way:

"Because of the fact that, he [participant's husband] was I suppose the one they respected, an ultimate authority, and he was Mr. fix it, nothing happened in their lives that couldn't be taken care of by their father." [CFM07]

"I used to try and protect her [participant's mother with dementia] or my family from that [her mother's eating habits], I'd be trying to clear off and tidy up and you know rushing around her not to have my family witness what she was doing ..." [CFM15]

8.3.2 'Dementia stimulated inter-relational labouring'

'Dementia stimulated inter-relational labouring' encompasses the actions that informal carers engage in because of dementia-stimulated contact with people or organisations. This property of 'inter-relational labouring' has two indicators: 'joining the informal network' and 'navigating the health and social care systems'.

8.3.2.1 'Joining the informal network'

Informal carers often locate and join an informal network of similar others with whom they can: identify, be identified by and belong to, and from which they can draw upon to enable them to engage in sustaining activities. Many of the participants in this study referred to the role and importance of this network, as these extracts illustrate:

"... the only person that understood was my neighbour down the road, she's done the home help. Her mother had senile dementia and it was only through her experience [that CFM09 found out what to do]..." [CFM09]

"We made a connection. A huge connection because all three of us [informal carers that met at a support group] were in the same boat ... Because they knew what you were talking about..." [CFM15]

"I wouldn't be able to look after mam without it [informal network] ..." [CFM17]

'Joining the informal network' involves creating and sustaining meaningful connections to other experienced or knowing carers. The transformation of informal carer social networks has previously been identified as an important dementia care phenomenon (Carpentier and Ducharme, 2003, 2005). O'Connor (2007) found that identifying oneself as a carer through interaction with similar others can combat caring associated isolation and enable the interpretation of dementia-related experiences and the ability to develop an authoritative voice. Duggleby et al (2009) further highlight the importance of supportive others to finding the positives in informal caring. However, contrasting with the function of connections to supportive others herein, Wuest, King Ericson and Noerager Stern (1994) and Morton (2003) refer to the benefits of connected support in terms of enabling informal carer progression further along a continuum towards separation from the person with dementia to residential care. In 'Sustaining our place', the informal network enables the inter-relatedness, collegiality and sense of belonging that is so central to having a place. A recent study by Halding, Wahl and Heggdal (2010), although relating to patients experiences of social relationships in a pulmonary rehabilitation setting, also found that group membership supports belonging and specifically a perception of commonality and fellowship with others. Morton (2003) similarly identifies the richness of the social interaction aspect of supportive similar others. In joining this network, informal carers are creating new contexts of interaction for themselves. They are also doing so for and with the person with dementia, where opportunities for engagement in previously known aspects of the life-world may be coming limited because they are perceived as threatening place. The importance of the contribution of the informal network to place can be understood from the words and the emotions inherent within the following informal carer extracts:

"We go to the Alzhemier Society, they have a little Friday morning club ... and every other week they take us [carer and her husband with dementia] on an outing." [CFM13]

"The small bit of contact [with carers in the support group] that I had, made me feel a bit more normal ..." [CFM20]

The informal network is also central to counterbalancing the experience of being set adrift from health and social services (Chapter 7, Section 7.4). This network can provide information and wise advice to enable the informal carer to engage in sustaining place, while managing progressive care needs. The importance of seeking information and supports, from informal and formal sources (Section 8.3.2.2), is supported in other dementia specific research (Quayhagen and Quaghagen, 1988; Wilson, 1989a; Lindgren, 1993; Butcher, Holkup and Buckwalter, 2001; Morton, 2003; Galvin, Todres and Richardson, 2005; Carpentier et al, 2008). In this study, the Alzheimer Society of Ireland was frequently identified as pivotal to this work. Interestingly however, the Society is generally not spoken about in the same tone as other formal health and social care services, which can be experienced as inhospitable and disconnected. Instead, the Society is perceived as part of an invaluable more person-centred support network within which personalised advice and/or people who live or have lived with and experienced dementia can be found. The informal network thus functions as a source of realistic and practical information. This network can imbue informal carers with knowledge and support, informational and social, to strengthen their ability to engage in many of the actions referred to in 'Sustaining our place', as these participants demonstrated:

"I didn't know anybody then that had Alzheimer's until I started going to the ... support group ... you have to educate yourself on it." [CFM09]

"Yes it [support meeting] is a time out and also it is information. It is like as if they inject drugs into you or something and you get so much information from listening to other people's stories ... The information you get from the other people there [informal carers attending support meetings] is brilliant ..." [CFM17]

Exposure to other carers' accounts of their experiences also enables informal carers to engage in making comparisons. In so doing, an informal carer can evaluate the various ways in which dementia can affect those whose lives it touches, including the impact on place:

"... for example, [name]'s brother-in-law also has it and poor [name of a person with dementia] had a stroke as well just to really cap the whole thing, but he went on the aggressive avenue ..." [CFM11]

"... there is a gentleman there [at support meetings] and he has to bring his wife [who has dementia] ... and God she is there and has no idea and I suppose that is the only way he has of getting out ... I am not as bad." [CFM14]

The informal network therefore enables the appreciation of the commonalities of the affects of dementia, while simultaneously reinforcing that all persons with dementia are unique. This in itself sustains place as it is consistent with an understanding of people as individuals with exclusive life stories.

8.3.2.2 'Navigating the health and social care systems'

This indicator of 'dementia stimulated inter-relational labouring' is identified by all of the research participants as a dynamic and time intensive aspect of 'Sustaining our place'. It involves an intricate set of actions designed to address 'negative health and social care contacting' (Chapter 7, Section 7.4). 'Navigating the health and social care systems' incorporates the following: 'beginning the journey', 'learning the system' and 'journeying on'.

8.3.2.2.1 'Beginning the journey'

In this theory, all informal carers and persons with dementia at some point begin to engage with health and/or social services. The central action associated with 'beginning the journey', involves initiating the process of formal assessment. In so doing, the informal carer's first port of call will usually be the general practitioner, as many participants described:

"And then I took her [participant's wife with dementia] down to [name] who's my GP, I went down and discussed it ... and he asked her a lot of questions ...and he noticed there was a distinct lack of memory and he said "well we better send her ... he made an appointment for her to get a brain scan ..." [CFM03]

" ... she would look at the fridge and not know what it was. Then I began to think it was a bit more. It was then I brought her to the GP." [CFM05]

In seeking assessment, the informal carer directly addresses the recognised problem with the intent to locate answers, receive official confirmation and facilitate access to specialist care and assistance. Receiving a diagnosis, or potential diagnosis, at this point can legitimate the threats to the place of the informal carer and person with dementia. However, if the initial working relationship with the general practitioner or other formal carer is not perceived as successful, then changes to place may not be quickly externally legitimated. This was the experience of the following participant who is now also working in the field of dementia:

"... but you see on the ground, when the primary was the GP, when they won't accept it [the presence of dementia], that's where you have difficulty." [AHPDO6 who was both an informal and formal carer]

While 'beginning the journey' is in some cases short lived, this action is of central importance to the sustenance of place. Early positive health and social care interaction can lessen the impact of negative contact with formal services and expedite the time it takes to attain specialist care. This in turn can increase the likelihood of attaining 'Sustained place' (Chapter 9).

8.3.2.2.2 'Learning the system'

'Learning the system' refers to the actions that informal carers use to navigate once they have entered the health and/or social care systems. Where being set adrift and going around in circles can be features of 'negative health and social care contacting' (Chapter 7, Section 7.4), 'learning the system' is perceived as a mechanism to counter such threats to place, as the informal carer attempts to assume a degree of autonomy and control. Two related actions can be identified. Firstly, informal carers will focus on finding the way. This is a form of experiential learning that can be informed by those within the informal network, but must be individually navigated because the route is not homogeneous for all, as these informal carers indicated:

"... I had to find the next stage myself." [CFM04]

"... you're trying to find something out that you didn't know absolutely nothing about in the first place, and you go, "well what questions do I ask?"." [CFM11]

This aspect of 'learning the system' is also recognised by those formal carers working within the specialist dementia care field. These experienced professionals recognise that due to insufficiencies within the health and social care systems, those whom the available services can most benefit, often must learn how to become connected rather than be connected, as this particular dementia care professional highlighted:

"... people will look to be referred to psychiatry of old age in the hope that they can be tied in with all the services that the whole team has to offer." [AHPDO5]

Finding the way can be smoother and faster if an informal carer encounters the appropriate service or a knowledgeable professional early on. However, where this is not the case there can be blockages and hold-ups along the way. If this occurs, an informal carer may decide not to pursue some routes. This is the second aspect of 'learning the system' and is used where efforts are perceived to be overly time intensive, unfruitful and unsupportive of place. Informal carers' descriptions of related experiences were particularly provocative in this study, as these extracts illustrate:

"I kept coming up against a wall ..." [CFM10]

"Isn't it enough to care for a person in your own home and do all you have to do, without if you do discover you need something. Like I got a letter in the other day about this grant ... Last year my daughter wrote off and got the form and I filled it in ...and we sent it back. They [service] said "yes you are certainly entitled to it and it will come automatically next year". But this year I got another form ok, which I have to get signed and take and get witnessed and you know half the time you say, should I bother ...everything is made difficult ... it takes too much time and effort." [CFM07]

8.3.2.2.3 'Journeying on'

In 'journeying on', informal carers are becoming more aware of what is required in order to sustain place in these contexts. Their focus is on locating specialist care and services that are, where possible, dementia specific and within which there is a greater chance that place will be respected and promoted. This differs from the similar action in 'learning the system' because in this indicator the informal carer's action is focused on a clear goal, as this participant explained:

"It [a particular service] is specially for Alzheimer's, yeah special group of people that look after the Alzheimer patients ..." [CFM06]

Not surprisingly, this need is also recognised by those formal care professionals who practice within specialist dementia services:

"The reality is ... persons with dementia really have very unique and complex needs that often can't be addressed through the more mainstream sort of statutory services." [AHPDO7]

Making connections is an important but frustrating aspect of 'journeying on'. Here it is the informal carer who may have to initiate contact with, or facilitate communication between, health and social care services/organisations, where he/she encounters disconnection and/or fragmentation. However, this action may in some ways address the experience of marginalisation that can occur within the health and social care services (Chapter 7, Section 7.4). The informal carers interviewed in this study provided numerous examples of how they engaged in making connections, as exemplified here:

"... when I go to the geriatric ward in [place name], they know nothing about dementia which doesn't make sense to me ...so you've got to track around the organisations yourself ... the other thing I do find difficult is that they don't all connect. The GP's doing his thing, the cardiologist is doing their thing ... they don't actually know what each other's doing and they don't connect" [CFM05]

"I mean four years of a gap before I decided I have to take my husband back [to be medically reviewed]." [CFM06]

When connections are made and the person with dementia and informal carer are in receipt of care/services, monitoring care promotes and protects place within the context of formal services. Monitoring care refers to the systematic and ongoing scrutiny and evaluation of formal care services by an informal carer. This action is particularly evident on contact with a new service or formal care context. Here the informal carer's trust must be earned, particularly where an informal carer has concerns about the level or quality of care available and potentially the ways in which the informal carer and person are perceived to be regarded. Monitoring care also occurs where progression in the degree of dementia is interpreted by informal carers as affecting the person with dementia's ability to monitor care on his/her own behalf. The manner in which the person with dementia is treated is therefore a primary focus of monitoring, as these participants explained:

"... he was very well looked after, it [care setting] was hospital based, you know? There was a matron and two assistant matrons and nurses and then there was students ... so they had a good quality of care." [CFM02]

"... I mean if mum had to go to hospital for anything, I think I'd be sitting beside the bed." [CFM04]

In this theory active vigilance on the part of the informal carer is central to the protection of the physical and psychological safety of the person with dementia as well as the sustenance of place, be this in the context of 'nurturative protecting' and/or 'inter-relational labouring'. This is similar to other research (Ching-Ching Chung, 1997; Parsons, 1997; Butcher, Holkup and Buckwalter, 2001; Caron and Bowers, 2003; O'Shea, 2003; Betts Adams, 2006). However, the data in this study suggest that monitoring care within the health and social care systems is a particular concern where a person with dementia, or informal carer, are exposed to formal services that are not dementia specific. An example of this referred to by participants was the acute care setting. Where deficits or insufficiencies in a particular service or setting are identified, an informal carer may move to take specific action (depending on the particular deficit). Examples of such actions include: exerting expertise (Section 8.4), making health care decisions, supplementing formal care or making an explicit request for specific care, illustrations of which were recounted by the following participants:

"We were offered two [respite settings], the first one we didn't take and I picked [name of care setting]... Oh three days, I took her out after three days. There was no way [that CFM12 could leave her mother with dementia there because of the nature of and manner in which the care was being given], and then I took her back home" [CFM12]

"... now I've been writing to the government to see if I can get anything, any help there, but there just doesn't seem to be an awful lot of help ..." [CFM06]

"I just say, this [care details] is what I want [for her mother with dementia]... I had done a small list ..." [CFM12]

Closely aligned to monitoring activities, is the seeking of ethical care. Herein, an informal carer emphasises his/her and the person with dementia's rights, not just to quantity of care but to safe, fair and humane treatment and quality of life, all of which are linked to the sustenance of place. This example was provided in the course of the joint interview in this study with the person with dementia and his wife:

"I think that the most important thing we're looking for at the moment, both of us, is quality of life. That's the only thing we can look for at this stage and I think that's, that is so important. I think all stops should be pulled out to give us that ..." [CFM13]

Previous research supports such actions. For example, Galvin, Todres and Richardson (2005) conceptualised the informal carer as an 'intimate mediator' between the public world of the health and social care systems and the private world of local knowledge arising from time spent living with the person with dementia. Similarly, Perry (2002) described how wives acted as interpreters in a forwards-backwards manner on behalf of and for their husbands. In this study, the seeking of ethical care relates to the informal carer in addition to the person with dementia. The data suggest that this is because ethical inter-relating may be an important component of the sustenance of place.

8.4 Enabling factors

Inherent in this component of the overall theory, there are a number of factors that can enable an informal carer to better engage in 'Sustaining our place' (Figure 8.1). The data suggest that these enabling factors are akin to a toolkit from which the informal carer can draw as and when required. They strengthen individual actions because when using them, the informal carer is acting from a stronger base. Thus, the more of these factors present, and the more conscious the informal carer is of their use, the better the likelihood that a carer will attain success in respect of 'Sustaining our place'. This is because the contribution of some enabling factors can be enhanced by others as will be shown below. In total, five enabling factors were conceptualised in this theory: knowing the person with dementia, perceiving caring as a moral way of being, developing expertise, having a frame of reference and strategising.

8.4.1 Knowing the person with dementia

This is the personal and intimate knowledge that the carer has of the person with dementia. Barnes (2006: 9) refers to such knowledge as "exclusive understanding of a particular person, gained from intensive interaction". This aspect of informal care has also been highlighted by

Champlin (2009). The informal carer often possesses unique and specific knowledge of: the person with dementia, and his/her abilities, needs (actual or potential) and general desires. Informal carers' narratives provided the following illustrations of this enabling factor:

".. so I formed the opinion then that she [participant's wife with dementia] knew that she was lacking in some element of memory, and, but she didn't want to talk about it." [CFM03]

"And I don't want a power like [in interactions with health and social care providers] or anything [like] that but I know this person [participant's mother with dementia]." [CFM15]

Actions to sustain place are thus enabled by the relational circle between the person with dementia and informal carer and the strength and depth of intimate knowing that resides within it. Such knowledge is unlikely to be held by anyone outside those closest to the person with dementia.

8.4.2 Perceiving caring as a moral way of being

Informal carers frequently portray caring as a moral endeavour, which enables appreciation of their humanity and that of the person with dementia. When drawing on this enabling factor, an informal carer is acting in the capacity of a moral agent, as exemplified in these extracts:

"...we call into the nursing home at different times, particularly at night, and if we do find that a patient ... not looked after, we're there to report that ...not just my father but any patient there." [CFM01]

"It [caring] is of course moral, I want to be there, I want to be there for mammy." [CFM15]

Perceiving care in this way enables meaning-making and may also facilitate continuance in the informal caring role. Hess (2003) identifies relationship as a key feature of what is a morally habitable world. Similarly in this study, regardless of the varied nature or quality of pre-dementia relationships, informal carers refer to caring as the right and desired thing for them in light of their reciprocal connections, past and present, with the person with dementia. This is supported by the findings of previous dementia research (Wilson, 1989a, 1989b; Gates, 2000; Zabalegui et al, 2008). When discussing caring in terms of moral action, informal carers in this study refer to mastering systems, obtaining rights and entitlements, and upholding citizenship as aspects of maintaining place (Section 8.3).

8.4.3 Developing expertise

The data suggest that two forms of expertise, gained primarily through experiential learning, can enable the sustenance of place. The first relates to knowing the person with dementia (point 8.4.1 above) and the second relates to the knowledge gained from personal experience of dementia, its impacts, consequences and others' reactions to its presence. Participants described this in different ways, for example:

"Oh, oh, very much so, very much so, I wouldn't been able to know, at least I would have been very uncomfortable three years ago, going down to a place like [place name], and meeting the, what do you call it, patients [persons with dementia] down there, and I wouldn't know what to say to them, now I can go in and I can talk to them ..." [CFM03]

"Like if I come across somebody now with someone who ... you know [has] dementia in their family, of course I have a very different approach to it because I understand it more." [CFM05]

This knowledge grows through prolonged engagement in the emotional, instrumental, personal, contacting, and monitoring caring activities identified as aspects of informal care by Hooyman and Kiyak (2008) and illustrated in the foregrounding literature explored in Chapter 3 (Sections 3.5.1 and 3.5.4).

8.4.4 Having a frame of reference

The development of the forms of expertise identified in Section 8.4.3 can be enhanced where an informal carer has a previous frame of reference, for example previous contact with or experience of caring for another person with dementia. A number of the participants referred to this:

"... it's not, this is not the first time this has happened to our family, this is the second time ... [CFM01]

"Yeah, do you know what I mean, my mother ... I'm dealing with her the same way my mother dealt with her mother, you know what I mean." [CFM04]

Some informal carers with such previous experience refer to its expediting and confidence boosting effects, as they can compare and contrast happenings, anticipate actual and potential problems and move to address them in a quicker and smoother manner.

8.4.5 Strategising

When drawing on this final enabling factor, informal carers use their expertise to devise and operationalise strategies with which to sustain place.[49] Where an informal carer has not yet developed sufficient expertise or lacks a frame of reference, strategising can still occur. However, the likelihood of a successful outcome to a particular strategy may be less, as trial and error may be the basis on which actions are implemented. The use of this form of learning by informal carers has previously been identified by Lindgren et al (1993) and Wilson (1989b), but in the context of acquiring skills of instrumental care and not in terms of strategising as an enablement to the sustenance of place. Strategising, in the context of 'Sustaining our place', also enables the exercise of control, involvement in advocacy on behalf of self and the person with dementia and may cause others to take notice of the informal carer and person with dementia. Becker (1997) identifies control as a core value used to manage uncertainty. In this study, the data suggest that having a sense of control may be very important for informal carers who strategise to sustain place.

8.5 Transitioning to 'Sustained place'

Where the sense of threat to one's place recedes and the indicators of 'sustained self' (Chapter 9, Section 9.2) start to be encountered, the transition to 'Sustained place' (Chapter 9) will usually commence. The mechanism by which transition is achieved is through informal carer engagement in an evaluative process in which the ongoing indexing of dementia-related events is used as the evidence on which decisions regarding place are made. It is within this context that temporality is an implicit feature of the theory, contributing to the transition between the theoretical components. The indexed or logged events are evaluated in terms of their meaning with regard to actual or potential threats to place, and not with regard to events in time as signals of the progression of dementia and/or its affects on the informal carer-person with dementia dyad or demands of caring.[50] This differs to other models of informal dementia care (Chapter 3, Section 3.5.4), in which temporality is central to describing caring in terms of stages, a career or a trajectory. The transition to 'Sustained place' occurs where an informal carer perceives that his/her and potentially the person with dementia's places are being recognised and respected in a valued and inclusive sense. Where this is not the case, an informal carer may continue to transition between 'Threatened place' and 'Sustaining our place' (Figure

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[49] These strategies are addressed in sections 8.2 and 8.3 above.

[50] The interpretation of events in terms of dementia progression may occur also but not within the context of this theory.

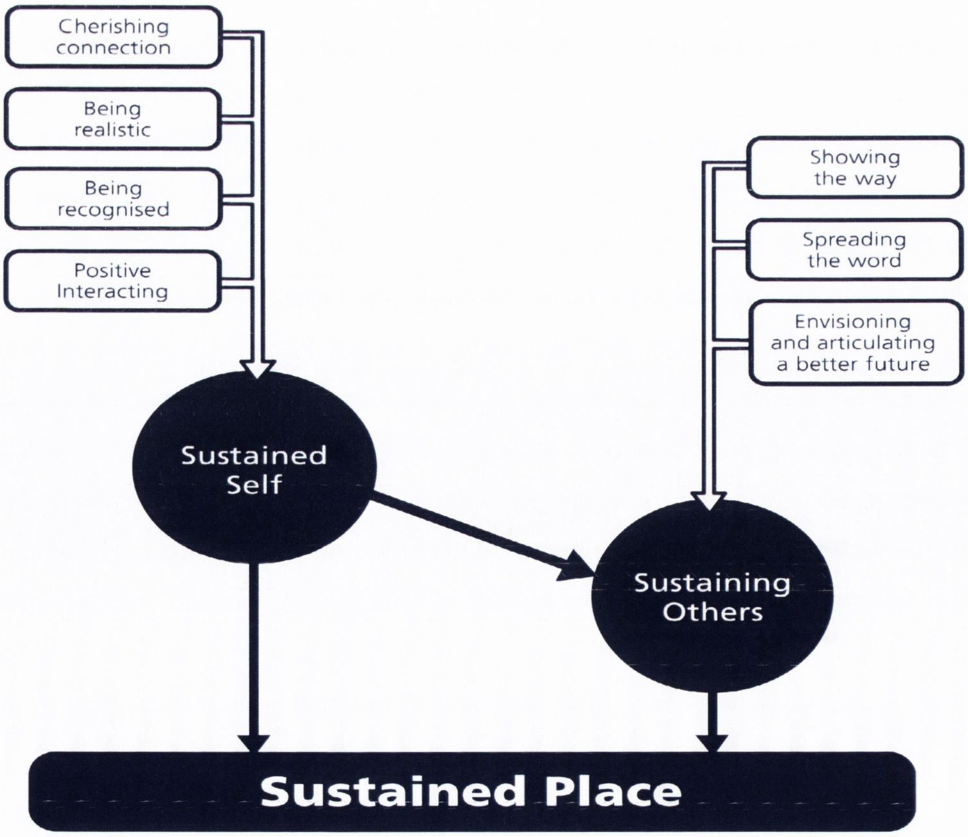
6.1). Thus, onward transition is only completed if the indicators of 'Threatened place' (Chapter 7) lessen and consequently the problem of 'Living on the fringes' is no longer perceived as an active threat. In the next chapter, the fourth and final component of the theory, which is called 'Sustained place', will be described.

Chapter 9 'Sustained Place'

9.1. Introduction to 'Sustained place'

This chapter presents the fourth and final component of the theory of 'Sustaining Place', which is 'Sustained place' (Figure 9.1). If 'Sustaining our place' is successfully navigated and the informal carer reaches 'Sustained place', a sense of place is restored. The problem of 'Living on the fringes' is addressed and the informal carer experiences coherence, belonging, citizenship and connection within the context of his/her life-world. However, this does not infer that the informal carer retains the same sense of place, as that experienced prior to the occurrence of dementia-related changes. Instead, while a sustained sense of place is experienced, it is re-defined and can differ in ontological, relational, ecological and contextual ways from that held before encountering the problem of 'Living on the fringes'. However, given the progressive nature of dementia, and the consequent impact on actual and potential relational experiences and opportunities, it is not a given that informal carers will remain in 'Sustained place'. As will be illustrated, there can be movement back to an earlier component of the process, although this is not synonymous with a return to a previously held sense of place.

Figure 9.1 'Sustained place'



Where informal carers reach 'Sustained place', they may then move to sustain other informal carers and sometimes other persons with dementia. This category is consequently comprised of two properties: 'sustained self' and 'sustaining others'.

9.2 'Sustained self'

Reaching 'sustained self' implies the regaining of a sense of relationship and situatedness - a recognised place within the context of various aspects of one's life-world. The sense of disconnection from the known aspects of the pre-dementia life-world is ameliorated. An informal carer experiences recognition and positive regard, within the context of interactions with other people, organisations and societal structures and spaces. This process consequently began with difference and ends with difference, in that 'Sustained self' relates to transforming differences encountered in the context of the problem of 'Living on the fringes'. Both biography and belongingness are restored. Where social devaluation and disconnection may have been perceived, there is now a perception of connection with and being valued, positively positioned and identified by those external to the informal carer-person with dementia dyad. As these informal carers described it:

"I am so thrilled to have [name of her home] and I am enjoying it ... But I am beginning to relax, sustain myself. I am working. I love my job. I am involved with the kids more. I can be there for them more. Listen to them more." [CFM15]

"Oh yeah, I am me." [CFM17]

As illustrated in Chapter 8, informal carers' actions within 'Sustaining our place' are directed towards also sustaining the place of the person with dementia. In terms of judgements of 'sustained self' in this regard, informal carers recognise that due to the nature of dementia they cannot definitively evaluate how persons with dementia perceive their situations, particularly as dementia progresses to its latter stages. However, such judgements do not hinge on knowing what the person with dementia thinks. They rest instead on judgements of the nature and outcomes of inter-relational encounters involving the person with dementia, themselves and others. To this end, in 'Unsettled place', the importance of indexing or logging dementia related events was demonstrated and this continues in 'sustained self', as the following exemplify:

"She [participant's mother with dementia] went to the [name of care service] the one on [name] street for I think about two months and that was extended because of my friend and

that, and they were fantastic and they actually did very specific activities for dementia, games and everyone was trained there that was in it and that was brilliant." [CFM05]

"I think every 6 months as well but after 2 years both of them [doctors] said right we've assessed you now, you're on the tablets there's nothing more we can do. There's no need for you to come back ..." [CFM13]

These events, once logged, place the informal carer and person with dementia centre stage and are used by the informal carer as evidence to evaluate the presence or absence of 'Sustained place'. This aspect of the process may not be consciously noted by an informal carer because it is embedded within the overall context of 'Sustaining Place'. The indicators of 'sustained self' are: 'cherishing connection', 'being realistic', 'being recognised' and 'positive interacting'.

9.2.1 'Cherishing connection'

For an informal carer, experiences of connection with the person with dementia, for example instances of recognition and reciprocity, provide evidence of an ongoing relationship between both. By supporting a sense of inter-relational belonging, such connections promote a perception of 'sustained self'. Even when instances of connection may diminish, they still have an uplifting affect. They reassure the informal carer that he/she is still a wife/husband/daughter/son/friend, who retains an important place in terms of this relationship. Person to person connections within the informal carer-person with dementia dyad are spoken about with joy, satisfaction and in terms of having the ability to make everything that one experiences a little better, if not worthwhile. The following informal carer interview extracts poignantly demonstrate that instances of connection are cherished, particularly where infrequent, and are a pivotal indicator of 'Sustained place':

"Sometimes you get a little bit of reaction ... my father said, mentioned my name to me, and that was better than winning the lottery ... magnificent every word he says ..." [CFM01]

"But from time to time there is a few seconds of lucidity ... oh the bon mo's [moments]. Absolutely. Yes. They are, they are really gems." [CFM18]

Where such connections with the person with dementia don't occur, informal carers may experience difficulty in terms of their place in this dyad. In such instances, an informal carer may accept any instance of recognition from the person with dementia, even if they are erroneously identified, as this daughter carer recounted:

"… but if she [participant's mother with dementia] called me [name], I didn't care, at least she knew me as somebody." [CFM10]

Where there is no recognition at all, there can be difficulty in maintaining 'sustained self' that may need to be compensated for by the other indicators of this categorical property. This particularly occurs very late in dementia and can be very emotional, as demonstrated here:

"I don't think he knows me any longer, both mentally and physically, we're not the same husband and wife you know …" [CFM06]

9.2.2 'Being realistic'

The data suggest that 'being realistic', in terms of the experiences an informal carer may encounter, and what can be achieved, supports 'sustained self'. This action is pragmatic and goal directed and it signifies a move away from the negativity and uncertainty that initially accompanies the confirmation of dementia and subsequent threats to sense of place. Duggleby et al (2009) found that coming to terms with the situation of dementia and dementia caring was an important component of renewing hope for informal carers. These researchers also indicated the importance of acceptance of dementia. However, the current study did not support this finding. Instead, in 'Sustaining Place', there is a realisation on the part of informal carers that dementia is present but not acceptance. As demonstrated in 'Unsettled place' (Chapter 6, Section 6.6), this realisation can co-exist in tension with resistance to dementia. For those informal carers with previous experience of dementia, there may be more knowledge regarding the road that lies ahead. In such cases, an informal carer will generally move to this indicator of 'sustained self' faster than a carer with little or no previous exposure to dementia. This is because in the presence of dementia-related experience, carers' expectations may be more viable than informal carers without prior knowledge or experience. The importance of 'being realistic' is supported by the following informal carers in this study, who spoke of needing to be realistic in their approach to dementia-related difficulties and what they could expect from themselves and others. This included the limitations within which they need to work to address 'Living on the fringes':

"I know it [bringing her mother with dementia home from residential care for a few hours] would be the wrong thing for her. I was going to bring her out Christmas Day. Somebody said to me is it for you or for her? I went home very upset …I said yeah it was for me … So I didn't bring her home." [CFM15]

"I said [to formal carer] "I'm not discussing it, he's coming home", and she said, "well, he may not", and I said, "no, it [admission to continuing care] isn't going to happen, it's not now", but by April I knew it had arrived" [AHPDO6 who was both an informal and formal carer]

'Being realistic' enables the sustenance of place by reducing expectations and demands placed on oneself. This is not to infer though that informal carers will accept lower standards of formal care or be passive in the face of threats to place. On the contrary, knowing what is achievable, for example in terms of social and healthcare interactions, can enable the pursuit of realistic actions, avoiding expenditure of time, energy and personal resources on unrealistic goals. The ability to be realistic seems to relate to the development of a personal understanding of dementia. As previously highlighted (Chapter 7, Section 7.3.3), for some of those interviewed, their initial perceptions of dementia were heavily influenced by their background, upbringing and commonly held discourses relating to dementia (such as those discussed in Chapter 2). However, informal carers indicate they undergo personal change in relation to their conceptions of what dementia is and how it is experienced. Having encountered dementia, long-held images and associations of dementia can be surfaced, acknowledged and unlearned, as shown here:

"I hadn't learned to differentiate between the difference between dementia and Alzheimer's, so like everybody else, I lumped it as Alzheimer's, and then I found there was a difference." [CFM07]

Having developed a personal understanding of dementia, and related experiences, expectations of what lies ahead can then be more realistic. This is also important when encountering the reactions of other people, organisations and society (Chapter 7), which can then be better understood. If such understanding exists, then the degree of threat, when experiences are less than positive or supportive, can be buffered somewhat. Informal carers' narratives suggest that where this is the case, they can interpret difficulties as being due to ignorance of the nature and consequences of dementia and/or the holding of traditional views of dementia and those labelled as having it, for example:

"I have a next door neighbour, the nicest person you can meet, but when she comes in, she can't talk to [participant's wife with dementia], she doesn't know her." [CFM03]

"They [other people] don't really know the ins and outs of it [dementia], but sure they don't have to have any need to know because it's not in their life. I mean the only reason like I know is because it's been in my life ... if it hadn't, would I want to know about it either?" [CFM04]

9.2.3 'Being recognised'

Recognition of the informal caring role is identified, by carers in this study, as an important contributor to 'sustained self'. Gates (2000: 57) highlights the importance of recognition, which she refers to as "confirmatory receiving" involving affirmation of the informal carer. In this theory, receiving recognition makes continuance in the role of informal carer a little easier and supports a perception of being a person of value and having a place, as this daughter carer explained:

"It's [recognition] a big relief ... makes you feel you have somebody at your back." [CFM16]

The importance of recognition is also illustrated in this fieldnote memo extract:

"I sat with CFM18 and he played his television interview for me ... in the interview and in our conversation reviewing biography was obvious ... how important this is to making clear the humanity in each [participant and his wife with dementia] and their status as people, citizens etc ... each had a provenance and in part recognition by others was central to its maintenance." [FNM CFM18]

Whereas the preferred and usual source of recognition is from those closest to the informal carer, such as kin relations and the person with dementia, recognition can also come from other sources, including: professionals, friends and even strangers encountered by chance. These sources are particularly important where recognition is not forthcoming from close family or where there are pre-existing or dementia-related difficulties in family relationships, as the following demonstrate:

"This new nurse, she brought two nurses from [place name] and she said I want you to look, this is the way they [persons with dementia] should be looked after." [CFM12]

"As soon as they [people in church] see me shuffling in with [participants wife with dementia], they think hello there is something wrong there ... then they become more fully aware that there is something wrong. But then they say "ah you're great"." [CFM18]

"And your friends are the people you least expect, the man across the road that you only say good morning too, he's there helping." [AHPDO2 who was both an informal and formal carer]

The nature of the recognition received is also varied. In some cases recognition is conceptualised in terms of moral support and for others in terms of experiencing acts of kindness and informal support. Informal carer participants provided the following examples of this:

"I mean my brother's girlfriend she'd be very fond of her [participant's mother with dementia] as well, she's very good to her and you know so that's somebody different outside of, you know, immediate family." [CFM04]

"... they [supportive friends] say "ah he [participant's husband with dementia] is looking good today" or "is it a step backwards today", they are the comments I want ... accept what's happening ... they're not going to give me any falsehoods ." [CFM07]

9.2.4 'Positive interacting'

Whereas negative contact with health and social care professionals and systems was identified as a strong indicator of 'Threatened place', 'positive interacting' is an important indicator of 'sustained self'. This refers to interactions with health and social care personnel and systems that confer a sense of recognition and the confirmation of the place and personhood of the person with dementia and informal carer, as recounted here:

"... the district nurse is a wonderful girl altogether. She was here yesterday. I suppose we talked for a couple of hours ..." [CFM03]

"I think I am getting such good [help], I think they [formal social care providers] are all so wonderfully ..." [CFM14]

For informal carers in this study, 'positive interacting' is primarily experienced when encountering those with specific skills and expertise in dementia and not necessarily in non-dementia specific health and social care contexts:

"... those people [day centre] are caring, lovely, they are very kind to me and Lord knows, those skills down in the day-care he goes, you couldn't pay them enough for what they do." [CFM07]

"... when they [persons with dementia] go to a hospital that are fully trained, the difference, you can see the difference, they understand the person ..." [CFM09]

Another important aspect of 'positive interacting' is being consulted in the course of health and social care interactions. Informal carers value being consulted, so that their expertise (Chapter 8, Section 8.4.3) is drawn on. The importance of valuing informal carers as experts has been highlighted by Nolan, Grant and Keady (1996) and Nolan et al (2003). Additionally, the importance of 'significance', or the experience that informal carers of older persons caring efforts are appreciated, is also a component of Nolan et al's (2004) 'Senses Framework' approach to care. In the context of 'positive interacting', being consulted can relate to assessments and evaluations of the person with dementia, where informal carers information may offer a more accurate picture than the administration of an objective test or the planning of services and supports. It is the informal carer who knows and can contribute the qualitative differences that can't be illustrated with numbers:

"... these clubs [for persons with dementia and informal carers] are very important ... they are good for the carer, 'cause the carer goes with the patient ... now they've sort of said ... the actual club is your club, so they ask you, "what would you think?", and a few of us said we would like to go on outings." [CFM06]

"he [doctor] asked me did I want her [participant's mother with dementia] to know what she had, and I said "no" 'cause I thought that would kill her" [CFM10]

'Positive interacting' consequently contributes to the 'Sustained place' of the person with dementia and the informal carer and indicates the interacting nature of the indicators of 'sustained self'. For example, 'positive interacting' can contribute to 'being recognised' and expands 'cherishing connection' beyond the informal carer-person with dementia dyad. Thus, the presence of a single indicator of 'sustained self' may be insufficient to infer the presence of 'Sustained place'. However, where an indicator may be only minimally present, a strong presence of other indicators may compensate for a deficit in one.

9.3 'Sustaining others'

Informal carers having grappled with the threats to their own and the person with dementia's sense of place, frequently move to help others to do what they have done in order to sustain their places. 'Sustaining others' may naturally stem from having positively benefited from 'joining the informal network' (described previously Chapter 8, Section 8.3.2.1) and wanting to do the same for others. In addition to the informational and practical supports this network provides, helping others may ferment the sense of community and belonging that connection with similar others conveys. Alternatively, 'sustaining others' may be a consequence of an informal carer having experienced 'Living on the fringes' and consequently wanting to enable others to lessen or address this problem. Those who engage in actions related to 'sustaining others', speak about having a 'Sustained place'. As such, informal carers who are immersed in actively sustaining their own and the person with dementia's sense of place, not having yet reached 'Sustained place', do not seem to consciously engage in 'sustaining others'. This leads to the suggestion that 'sustained self' is a pre-requisite for 'sustaining others', as the following illustrate:

"Because I can step back a little bit more now. When you are in the middle of it you can't ... when you are going through those stages ... you don't actually see them." [CFM15]

"I would like to think that I could help people. Probably sometime, not now because I am still kind of in the thick of it." [CFM19]

'Sustaining others' may take different forms and can occur subtly, for example through the giving of informal advice. Alternatively, 'sustaining others' may take the form of a deliberate and active sustenance, such as taking on voluntary roles on help-lines or a paid role in the field. This was the case for two of the participants in this study (AHPDO2 and AHPDO6). The indicators of 'sustaining others' are: 'showing the way', 'spreading the word' and 'envisioning and articulating a better future'.

9.3.1 'Showing the way'

An informal carer having engaged in 'Sustaining Place', may in turn become a guide or resource for others encountering, or with the potential to encounter, the problem of 'Living on the fringes'. 'Showing the way' can encompass three actions: the giving of information, informal support and the enabling of access to appropriate sources of information or service supports. In relation to giving information, those interviewed consider 'showing the way' of vital importance to those who: suspect dementia but don't know what actions to take, feel abandoned by relational interactants or feel set adrift from the healthcare system with a diagnosis and little else to assist them. Informal carer participants provided the following examples of this:

"... she [woman in a restaurant] caught up on me ... "excuse me" she says, "I heard you talking to the waitress ... about your missus [wife] ... what way does it work", ... "Why says I, why are you asking me?" ... "I have a sister she says, I think she's getting the same thing. She can't remember things like that. She talks silly at times". Right now! That's it! You want to get her to a doctor." [CFM08]

"I am down on the newsletter from the church, as the contact person for the Alzheimer's in [place name]. And they [people] ring up and they expect somebody to be able to converse with ..." [CFM18]

Enabling access is a deeper level of involvement in 'sustaining others' that may simultaneously enhance the perception of 'sustained self'. Having been there themselves, the informal carer takes comfort in the provision of solace, support and guidance to another who is finding or had the potential to find place threatened through similar circumstances. The informal carer in a sense hands over his/her personal map, or a more streamlined version, as having gained first hand experience the journey may be simplified for another. The following extracts support this action, demonstrating how advice about avoiding unhelpful contacts or experiences may be offered:

"I would like to think that I could help people. That my experience would help other people. Maybe you shouldn't do that or maybe this is the road you go down" [CFM19]

"... when the lady came into me I asked her; "did you consider a second opinion", even if she was sure, you know and she accepted his decision I said; "did you ask for a second opinion", and she said; "no", I said. "did you have an MRI, did you ask?", because I explained to her about the dementia centre in (name)" [AHPDO2 who was both an informal and formal carer]

The contexts within which 'showing the way' occurs can vary. Where it becomes known that an informal carer has experience of dementia, they are sometimes contacted by those seeking advice or direction:

"I find that sometimes people ring me up here, people locally, because they know what has happened, you know, and they would ring me and ask for some help or advice, or you know, "could I tell them where to go or what to do?" ..." [CFM02]

In other cases, informal carers take the initiative and make contact, as these participants highlighted:

"I had put other people on to [formal] carers, you know, they don't know where to go, and because other people know that my mother has Alzheimer's and that I have a carer now ..." [CFM04]

"I would put it this way, I would nearly be able, if I seen somebody confused or whatever, I would, I would be able to nearly tell you that person has Alzheimer's, I would watch the signs first, and if anybody said to me that a person in their fifty's or forty's have got Alzheimer's, I think I would be the first one to get in touch with that family to see could I do something for them, because I would know that help was not there." [CFM09]

The data support 'showing the way' in two ways: firstly, informal carer participants' accounts of how they helped others and secondly participants' accounts of being helped by others when experiencing 'Threatened place'. 'Showing the way' is then a two way process, in that when experiencing 'Threatened place' an informal carer may be shown the way by those experiencing 'Sustained place' and when or if 'Sustained place' is reached he/she may show others the way. The provision of information and the enablement of access are consequently indicative of informal carers becoming a resource for others.

9.3.2 'Spreading the word'

'Spreading the word' is a wider role than the preceding indicator. It was spoken about by some informal carers who identified a lack of dementia knowledge and understanding in the public or lay domain, as significantly contributing to the problem of 'Living on the fringes'. The data suggest that informal carers are keen to encourage debate and discussion in relation to dementia. For example, some informal carers address the dearth of knowledge and understanding by taking an active role in educating others, advocating for more public education or challenging perceptions of dementia. Examples of 'spreading the word' from the data include:

"I couldn't explain to people enough, I myself go into schools and I talk to students, transition years, I talk to them about Alzheimer's, and my experience with my family, and I point out to them, you know that ... even if they haven't got Alzheimer's patients ... how important it is for a young person to go and visit a nursing home." [CFM01]

"Well, I was on a [radio] programme on (name of radio station), and I was asked several questions ..." [CFM06]

"And I think by our presence, we [this informal carer and his wife] walk out, everybody in this road knows about [participant's wife with dementia] and myself…" [CFM18]

The need to spread the word can be related to the recognition that many of the experiences that contribute to 'Living on the fringes' can be linked to societal understandings of dementia, which are culturally embedded and socially constructed, as was demonstrated in Chapter 2. It is also linked to informal carers' beliefs that enhanced understanding could help those who have little or no knowledge of dementia, for example those who may encounter people whose lives are touched by dementia or who could potentially have dementia in their own lives at some point.

9.3.3 'Envisioning and articulating a better future'

In the final indicator of 'sustaining others', informal carers identify the need for people, systems and society to be accepting of and ready to accommodate dementia-related changes in terms of the person with dementia and informal carers. In 'envisioning and articulating a better future', informal carers have interpreted their experiences and can identify how things need to change, in order to support the continuance of place and decrease the problem of 'Living on the fringes'. The data suggest the beginnings of change in understanding and tolerance for persons with dementia, if not for dementia. This is related by informal carers in this study to increasing knowledge and public campaigns, which bring the hidden disability of dementia out into the open thereby making it more amenable to debate:

"I think society is much more aware of it [dementia], you know?" [CFM02]

"And I think people are talking about it [dementia] more …" [CFM04]

However, while it is recognised that perceptions of dementia seem to be changing, informal carers conceptualise how change needs to increase in pace so that the situations of future informal carers and persons with dementia could be bettered. Therefore, the changes envisaged are those that could potentially avoid the need for 'Sustaining Place'. To this end, informal carers envision a better future and having done so can articulate explicit recommendations for the changes and interventions they perceive necessary. These suggestions stem from the actual experiences of informal carers, persons with dementia and in some cases the professionals who participated in this study, particularly those interviewed who chose to take roles in dementia care due to their personal experiences with dementia. As such, they are recommendations that those most closely impacted upon by dementia, and its social consequences, consider will make a meaningful difference. Firstly, the need to facilitate attitude change and enhance societal understanding was identified by participants in this study, as a fundamental means to improve understanding of dementia, as recounted by this informal carer:

"I still think there's a huge lack of education for people who don't have firsthand experience of it [dementia]. That needs to be maybe addressed or dealt with or just the fear taken out of it" [CFM05]

This contention was supported by the following disability organisation representative:

"…I think that a focus on prejudice, discrimination and shifting attitudes by showing that the issue is not in the person but it's in the environment. It's in society …" [AHPDO10]

Education is the preferred approach to achieving the above. The health and social care professionals interviewed in this study identified that to be effective such education would need to employ multiple approaches and target multiple age cohorts. In addition, these participants identified a need for naturalistic contact with persons with dementia and dementia specific education and experience for those involved in delivering dementia-related supports and services, for example:

"… you know promote a more holistic and bio-psychosocial model of dementia care and seeing dementia more as a disability. And I think that that would help in the whole process of trying to advocate for people and trying to de-stigmatise." [AHPDO7]

"And I suppose you know education of all professionals, architects, engineers, lawyers, etc…." [AHPDO7]

The nature and enhancement of the experience of health and social care services also requires attention. In particular, informal carers, and the person with dementia interviewed, identified the need for services to be flexible, to talk with each other and for designated professionals with requisite skills and sensitivity to enable guidance, support and the voice of the informal carer and person with dementia to be heard:

"… the other thing I do find difficult is that they don't all connect. The GP's doing his thing, the cardiologist is doing their thing, the Alzheimer's Society's here and they don't actually know what each other is doing." [CFM05]

"I think the first thing is you need some sort of communication group who can tell you what you can get."[PWD1]

Finally, to advance the experiences of persons with dementia and informal carers, dementia as a policy issue needs to be prioritised. Without this, and the resources to support dementia care, little progress is possible, as the following extracts demonstrate:

"I think you have to be so much hands on and I think the guys up there who are ruling all this needs to get a reality check of what is really going on ..." [CFM19]

"The participant after the interview referred to the need for multi-level interventions to address the issues discussed." [FNM CFM09]

This need for enhanced policy support was also recognised by some of the professionals interviewed:

"You see clearly until there's a broader policy support for persons with dementia, it's very hard for individuals to deal with these issues." [AHPDO10]

The recommendations identified in 'envisioning and articulating a better future' target personal, organisational and societal structures and spaces, reflecting the nexus within which threats to sense of place are experienced and addressed. The articulation of recommendations and informal carers' concerns and actions to improve the plight of others, also emphasise the meaning-making occurring throughout the theory of 'Sustaining Place'. Informal carers are clearly not simply acting. They are acting with deliberate intent to address what is of concern to them and what matters is conceptualised from the experience of diverse inter-relational encounters, or restrictions on such encounters, within and across informal carers' life-worlds.

9.4 Potentially transitioning to 'Threatened Place'

As previously explained (Chapter 6, Section 6.2), the theory of 'Sustaining Place' is not linear in that many informal carers may return to an earlier component of the process, specifically 'Threatened place'. This may occur for a number of reasons. Attempts to maintain social connectivity may be unsuccessful if others' social expectations cannot be met and/or negative relational encounters occur or recur. The inter-relational consequences of progressions in dementia can also bring the informal carer and person with dementia back into contact with the indicators of 'Threatened place' (Chapter 7). Examples of this include: increasing difficulty in communication and social functioning for the person with dementia and informal carers' difficulties in maintaining social contact, as this memo extract demonstrates:

"It was easier to be with her mum [who had dementia] than society. This she said was sad and made the experience so much worse. There were illustrations of the loop-back nature of the theory, she spoke of being sustained and then something would happen that would send her back to threatened place." [FNM CFM19]

If the informal carer moves back to 'Threatened place' and then onto 'Sustaining our place' again, the ability to engage in 'sustaining others' is compromised because the informal carer is once again oriented to self and person with dementia working. The ability to think wider is difficult, for example in terms of actively seeking to help other informal carers or persons with dementia; although if information is sought by another, for example in the context of a carer support meeting, this can be accommodated. Once again, the informal carer is actively confronting the problem of 'Living on the fringes'. If the person subsequently emerges from 'Sustaining our place' and moves back into 'Sustained place', a greater possibility to actively sustain others returns where 'sustained self' is attained. This supports the inter-locking nature of the components of the overall basic social process conceptualised in the theory of 'Sustaining Place'.

9.5 In summary

Chapters 6-9 presented the theory of 'Sustaining Place'. This theory is a basic social process, which was conceptualised using CGT methodology (Chapters 4-5). 'Sustaining Place' is composed of four inter-related components: 'Unsettled place', 'Threatened place', 'Sustaining our place' and 'Sustained place'. These theoretical components account for how informal carers of persons with dementia address the problem of 'Living on the fringes', which is interpreted by carers as threatening their place and that of persons with dementia. In the next chapter, the theory will be discussed and 'Sustaining Place' will be considered in terms of being a novel way of understanding the phenomenon of informal dementia care.

Chapter 10 Discussion: 'Sustaining Place' in Context

10.1 Introduction

As Chapters 6-9 elucidated, the theory of *'Sustaining Place'* conceptualises the basic social process informal carers of persons with dementia engage in to address the problem of *'Living on the fringes'*. This chapter will provide a consideration of *'Sustaining Place'* in the context of what is already known. While comparisons and contrasts were previously drawn between the theory and some of the existing informal dementia care research, the purpose of the discussion in this chapter is broader in nature. As such, this chapter will demonstrate how the theory of *'Sustaining Place'* both contributes to and expands extant debates in a number of related fields in dementia. This chapter does not aim to unsettle, confirm or refute pre-existing theoretical frameworks that illuminate aspects of the experience of informal dementia care. Instead, by providing a fresh perspective on the phenomenon, the focus is on how the theory of *'Sustaining Place'* adds to an expanded epistemological understanding of the meaning and experience of living with dementia, from the perspective of informal carers. In so doing, the concepts and issues that will be addressed are those that underpin the originating problem, substantive theory and the constituent actions identified within *'Sustaining Place'*. To this end, the following will be examined having emerged as salient to a comprehensive consideration of the theory:

10.3 The importance of place,
10.4 Having a place – belonging,
10.5 Endangered place - affronts to place and belonging and
10.6 'Sustaining Place' - challenging disconnection, enabling citizenship.

To set the context for the discussion, a brief contextualising summary of the theory of 'Sustaining Place' will be presented before examining each of the above.

10.2 'Sustaining Place' – a summary

Chapter 3 demonstrated that to date the phenomenon of informal dementia care has primarily been understood in relation to: its constituent activities, impacts and consequences, burden, stress and coping perspectives and as a temporal process unfolding across the progressive course of dementia. However, in exploring the related literature and that relating to the discursive construction of dementia, it emerged that additional perspectives are required to best support and enhance quality of life for informal carers and persons with dementia. In recognising this, it became apparent that such perspectives need to be developed by looking outwards beyond the intra-psychic and inter-relational experiences of caring between the informal carer and person with dementia. This is because a critical review of current knowledge demonstrates that the social experiences and related processes involved in the informal caring role have not yet been sufficiently accounted for. Consequently, this thesis is underpinned by the understanding that informal dementia care cannot be considered in isolation from the macro-contextual influences that situate informal carers' experiences and interactions with other people, organisations and society. It was from this position, formulated over the course of the study, that the problem of *'Living on the fringes'* and the substantive CGT of *'Sustaining Place'* which addresses it were conceptualised. Figure 10.1 presents a diagrammatic representation of the relationship between *'Living on the fringes'* and the categorical components of *'Sustaining Place'*.[51]

The problem of *'Living on the fringes'* is encountered when an informal carer experiences alteration to his/her relationship with and place in the life-world, which is accompanied by an equal concern for the place of the person with dementia. The data collected in this study illustrate that this problem is stimulated in two ways: 1. dementia-related stigma and 2. living a different life. My analysis demonstrated that the ways in which informal carers experience and respond to *'Living on the fringes'* are multifaceted and dynamic, and best conceptualised in terms of the basic social process of *'Sustaining Place'*. This theory is composed of the four inter-related categorical components presented in chapters 6 to 9. These are:

- *'Unsettled place'*, in which a sense of difference in taken for granted life-worlds is recognised by informal carers,
- *'Threatened place'*, in which there is a disruption to belongingness, purpose and directionality, building to informal carers' recognition of the need to take action,
- *'Sustaining our place'*, in which informal carers engage in specific actions to sustain their place and that of the person with dementia in the contexts of their life-worlds and
- *'Sustained place'*, which informal carers attain if the problem of *'Living on the fringes'* is successfully addressed and a sense of place is restored.

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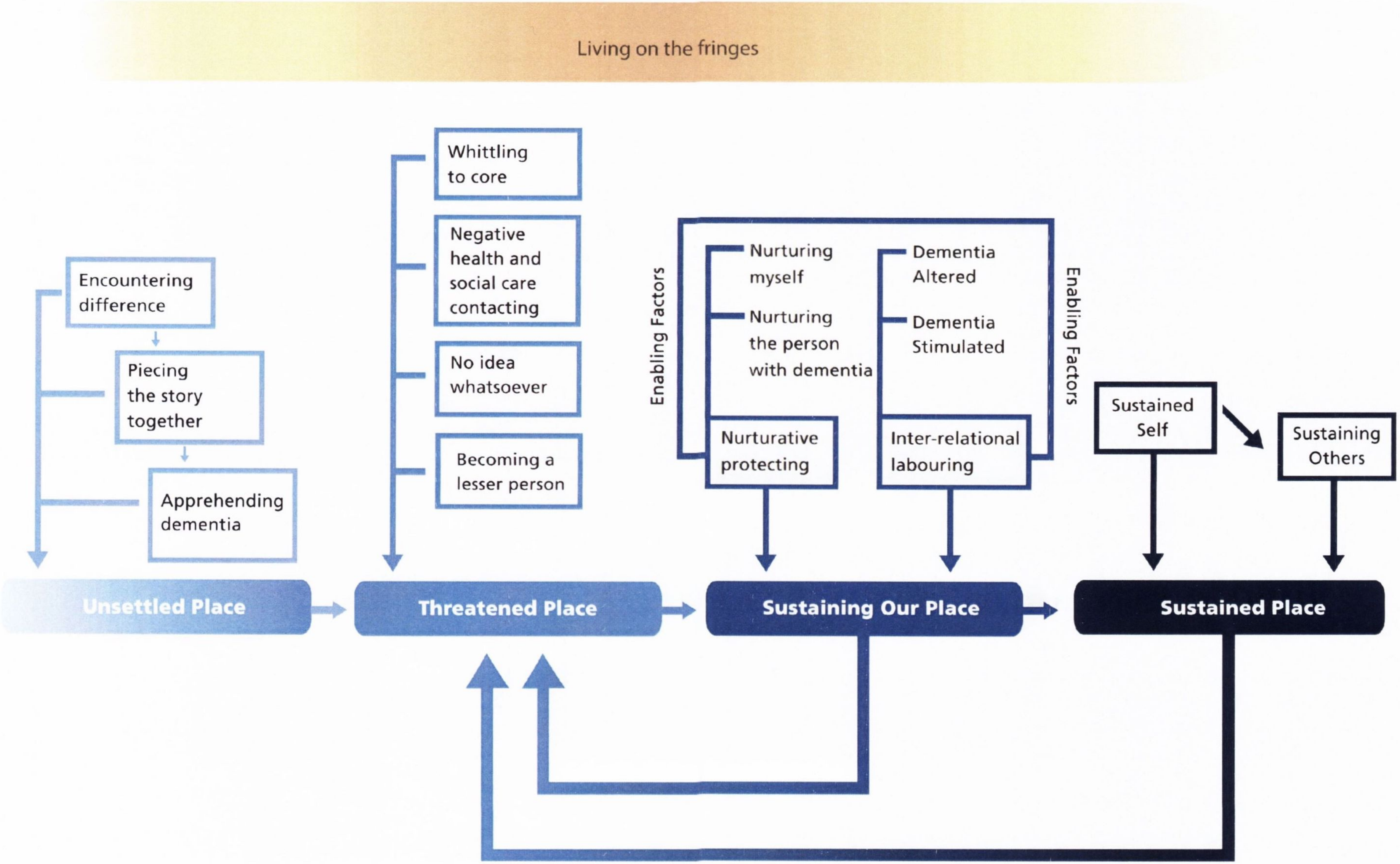
[51] Figure 10.1 provides an overview of each of the theory's categories together with their properties. The indicators of each category's properties are provided in the textual description of the theory and in the individual categorical diagrams presented in chapters 6-9.

Figure 10.1 Overview of the theory of 'Sustaining Place' in relation to the problem of 'Living on the fringes'



Each of these categories was conceptualised by means of the CGT (Glaser, 1978, 1992, 2001, 2003, 2005) methodology and a social constructionist epistemological orientation. Using this methodology enabled the elucidation of the latent patterns engaged in by informal carers of persons with dementia to address concerns they encounter in the context of their social lives and related interactions. As can be seen in Figure 10.1, the resultant theory of *'Sustaining Place'* is dynamic in that the interlocking nature of *'Threatened place'*, *'Sustaining our place'* and *'Sustained place'* account for the individual ways in which informal carers can move between theoretical sub-components. However, *'Sustaining our place'* is the core category as it explains the majority of the actions engaged in by informal carers to address *'Living on the fringes'*. This is because the actions contained within *'nurturative protecting'* and *'inter-relational labouring'*, account for the majority of the latent social behaviours that informal carers use to sustain their place and that of persons with dementia. As Figure 10.1 illustrates, the problem of *'Living on the fringes'* is increasingly acute as the informal carer moves through *'Unsettled place'* and *'Threatened place'* and it begins to progressively decrease throughout *'Sustaining our place'*.[52] Where an informal carer attains *'Sustained place'*, they are no longer acutely experiencing *'Living on the fringes'*. However, if an informal carer moves back to *'Threatened place'* they once again are actively experiencing and interpreting the problem of *'Living on fringes'*.

In the course of the analysis, it became clear that the actions contained within the components of *'Sustaining Place'* occur as a result of the understandings arising from and consequences of the discourses that construct dementia and informal dementia care. These socially constructed discourses function as powerful mechanisms that people, organisations and society draw on to position and behave towards those who live with dementia. In so doing, they contribute to the creation of the problem of *'Living on the fringes'* resulting in a significant and generally negative alteration of the informal carer's and person with dementia's relationships with and places within their life-worlds. The CGT of *'Sustaining Place'* illustrates how informal carers engage in a multiplicity of intricate social actions to sustain their place and that of persons with dementia in response to this problem. These actions suggest that in protecting, defending and sustaining what matters most to them, informal carers are exerting their right to citizenship in the context of inter-relational encounters or alterations to opportunities for same. Therefore, the theory of *'Sustaining Place'* illuminates informal dementia care in the context of the social domains and socially constructed understandings in which it is experienced and the problem of *'Living on the fringes'* is resisted. In the following sections, the contribution of the theory of

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[52] This is illustrated in the use of the increasing and decreasing colour intensity in the section of Figure 10.1 representing the problem of 'Living on the fringes'.

'Sustaining Place' will be considered in terms of its ability to broaden the discursive construction of the phenomenon of informal dementia care.

10.3 The importance of place

The theory of *'Sustaining Place'* demonstrates that the interpretation and experience of dementia includes, and yet is located beyond, those immediately touched by it, including informal carers. Adams (2008) concurs that other people and agencies clearly affect the totality of the experience. Milligan (2003) and Victor (2005) further highlight that caring is located within private and public spaces but that the creation of an overly rigid demarcation between the two is artificial because boundaries are increasingly less clear. In consequence, a much broader appreciation of the "complex web of relationships" in which informal care is located is required (Forbat, 2008: 227). This suggests that dementia might better be located within the spaces between people (Forbat, 2008). Conceptualising the experience of dementia in this way, contrasts with understandings localised within the person or within the informal carer-person with dementia dyad as has frequently been the case in the past. It also contrasts with descriptions of dementia care in particular physical spaces, for example: acute, residential or home care settings. In the theory of *'Sustaining Place'*, the meaning and importance of place is much broader than suggested in these perspectives because the data in this study suggest that place cannot be localised within a particular person, relationship or setting. As such, the need to engage in *'Sustaining Place'* can occur simultaneously in multiple domains of an informal carer's life. This section will consequently explain and examine the meaning and importance of place, as it relates to the experience of dementia for informal carers in this study.

Both the problem of *'Living on the fringes'* and the theory of *'Sustaining Place'* illustrate that having a place is important, even though the word 'place' may not have been explicitly articulated by informal carers. The concept of place is important because it is recognised by informal carers and others with whom they inter-relate. According to Pearlin et al (1990), no matter how seemingly random an occurrence is, for example dementia, related experiences are somewhat controlled and led by societal orders and the position of people within society. This supports the appropriateness of the centralisation of place in *'Sustaining Place'* because it illustrates the embedded nature of informal dementia care within a matrix of social relationships. As the introduction to the theory in Chapter 6 explained, place is understood in this study in terms of people's situatedness within and among other people, organisational and societal structures and spaces encountered in their life-worlds. The data from which *'Sustaining Place'* was conceptualised demonstrate that the experience and interpretation of having (or not having) a place is mediated within relational interactions (or disruptions thereof). For example, informal carers' narratives referred to inter-relational encounters with family, friends, colleagues and health and social care professionals as some of the contexts within which they interpreted either threats to or confirmation of place.

It is only when acutely threatened, for example when experiencing the problem of *'Living on fringes'* that a heightened awareness of place and its importance surfaces for informal carers. The data suggest that this occurs because in the presence of dementia, and others' reactions to it, the perception of occupying a recognised place and being positively regarded, valued and accepted can be compromised. Therefore, in the theory of *'Sustaining Place'*, the intrusion of dementia-related changes into informal carers' mainly organised, regulated and taken for granted pre-caring life-worlds, poses a significant threat to their sense of place. This threat increases as informal carers move through *'Unsettled place'* and *'Threatened place'*, which are the first and second components of the theory. Also central to the actions and experiences inherent in *'Sustaining Place'*, is that this threat creates equal concerns for informal carers regarding the place of the person with dementia. Similarly, Crooks (2007: 578) identifies the difficulties that illness brings in terms of disruption to socio-spatial worlds and daily geographies, which are "the places, routes and paths" that people use in living lives. Illness related disruption to life-worlds and biographical disturbance has received attention by researchers (Dyck, 1995). However, such attention has not necessarily been given to the experience of informal carers of persons with dementia. Where it has, the interpretation of place can differ between researchers depending on their particular orientation. For example, place is a focus of concern within such fields as: social geography, social gerontology, anthropology, architecture and environmental psychology. However, the concept of 'place', as it is conceptualised in this study, may not previously have been explored in great depth because some of the informal carer research has tended to be reductive. Such research begins with researcher identified components of the experience as a focus of enquiry. Some of this research was explored in Chapter 3 and has focused on a range of important subjects, including: the demographics of informal caring, the influence of gender, the impacts and consequences of informal caring and explorations of the burdens and stresses of the role and ways of coping.

However, the use of a CGT approach in this study facilitated the conceptualisation of informal carer identified concerns and consequently enabled the discovery of place as an issue of pressing concern to carers. Consistent with a social constructionist orientation, I then focused on the problem of place in the context of this study. By adopting a questioning stance towards the data, I was enabled to identify how informal carers managed the disruption to the sense of place inherent within the problem of *'Living on the fringes'*. In so doing, the factors that could be influencing the construction of the meaning and actions relating to this problem were considered. This facilitated my appreciation of the inter-subjective construction of understanding occurring in the context of informal carers' social lives. The impact of the ways in which dementia and informal dementia care were socially constructed and understood, by the various social actors referred to in informal carers' narratives, were then recognised to be influential in the theory.[53] This recognition enabled me to understand how dementia-related understandings support some social action patterns, while militating against others. This was a critical juncture in the construction of *'Sustaining Place'* because as Burr (2003) and Gergen (2009) highlight, socially constructed understandings create the limits that define how people act and behave towards one another.

Importantly however, the theory of *'Sustaining Place'* does not imply that successful movement through all four components of the process will result in the sustenance of ways of being in and relating to the life-world as they were experienced before the caregiving role. Instead, where *'Sustained place'* is reached, the nature of place differs in ontological, relational, ecological and contextual ways from that held before encountering the problem of *'Living on the fringes'*. In recognising the right to place, the theory does not therefore suggest that place is static or that webs of relationships and involvement in various aspects of the life-world don't change over time. This is clearly not the case because the dissolution of some social networks and the formation of new ones is evident within the theory, for example in *'whittling to core' ('Threatened place')* and *'joining the informal network' ('Sustaining our place')*. Instead, an underpinning premise of this theory is that change is an integral feature of place over the course of all people's lives. This was highlighted particularly when informal carers engaged in recounting biography, within the context of *'Sustaining our place'*, illustrating the individuality of each person's life-story. Therefore, in contrast to being static, a person's place in-the-world is dynamic and evolving as there is recognition of the temporalities of life and a sense of expected onward movement. Understanding place in this way implies that life situations that induce change, such as dementia, should be amenable to interpersonal, organisational and societal accommodation. Where this is not experienced by informal carers in this study, the problem of *'Living on the fringes'* becomes a reality and the need to engage in *'Sustaining Place'* then becomes manifest.

The emphasis on 'place' within *'Sustaining Place'* consequently provides a broader lens with which to conceptualise informal dementia care, than many existing theoretical conceptualisations of the phenomenon. For example, the theory may offer a means to widen the inward focus inherent in the concept of personhood in dementia, which is described by Kitwood

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[53] The foregrounding literature in Chapters 2 and 3 explore these understandings.

(1997). In much dementia related literature, it is the personhood of the person with dementia that is generally identified as at risk, if not eroded, by way of dementia progression and the ways in which those around the person act. However, while regarded as seminal, Kitwood's (1993a, 1993b, 1997) work has been critiqued as in some ways limited because personhood is dependent on others for its creation, sustenance and recognition. Also, the focus on the person with dementia neglects the wider context in which the person is situated (Baldwin and Capstick, 2007; Bartlett and O'Connor, 2007; Baldwin, 2008b). Despite this, a key benefit of personhood is that, similar to *'Sustaining Place'*, it does centralise the importance of relationship and emphasises connectedness and inter-relationality (Kitwood, 1997; Bond, 2001). Additionally, contemporary developments have expanded the way in which personhood is understood. For example, O'Connor et al (2007) propose that personhood is best conceptualised in terms of three intersecting domains: 1. subjective experience, 2. interactional environment and 3. socio-cultural context. Importantly, *'Sustaining Place'* may extend understanding even further. This is because in this theory, the place and actions of the informal carer and others are centralised alongside those of the person with dementia. Thus in *'Sustaining Place'*, inter-connectivity between all people and their life-worlds is underscored, and inter-relationality and interdependence are identified as key features of living and sustaining a sense of place. Therefore, the way in which place is understood in the theory calls attention to people's right to an embedded existence, if so desired. For example, informal carers in this study referred to the importance of their situatedness in their families, and local social and religious communities and the lengths they went to sustain their places within these communities. The interpretation of place is consequently not limited to a particular physical setting, nor is the phenomenon experienced by informal carers within a singular set of interactions.

As highlighted previously in this thesis, recognition of the need to broaden the focus of understanding in relation to dementia does exist. This has led to the emergence of expanded professional approaches to dementia care, including relationship-centred care (Nolan et al, 2002; Nolan et al, 2004; Forbat, 2008; Ryan et al, 2008) and whole systems approaches (Adams, 2008). However, the theory of *'Sustaining Place'* encourages consideration of place in broader terms again by extending the focus of concern to all those who inter-relate with the informal carer and person with dementia within and across their life-worlds. Similar to the way in which place is conceptualised here, McHugh (2003) who draws on social geography, suggests that the concept is an enmeshed aspect of the social worlds, which people inhabit and that identity is indivisible from place. However, much of the available literature relating to place tends to emphasise particular physical environments in relation to social relations and people's interpretation and experiences of 'space and place'. For example, McCormack (2004: 34) identifies "being in place" as a core concept of person-centredness in gerontological nursing, using the term to refer to the specific physical "milieu of care". Diaz Moore (2004: 300) further defines place as ""the socially shared aspects of experience" ... a milieu comprised of a physical setting within which activities occur – which can be thought to be carried out by people of various social groups".[54] While the meaning of place in *'Sustaining Place'* is inclusive of physicality, embodiment, interpretation and relatedness, it is more expansive.

The importance of centralising place in *'Sustaining Place'* is consequently two-fold. Firstly, it emphasises the need to consider the impact and experience of intimate social interactions on the interpretation of living with dementia and the experience of informal dementia care. This is because informal carers in this study continually referred to the influence of some social interactions with other known and unknown people as contributing to *'Threatened place'*. In contrast, other more positive social interactions contributed to *'Sustained place'*. It is also supported by the wider caring literature, which recognises that the giving of care is a relational experience (Garey et al, 2002; Barnes and Brannelly, 2008). Secondly, centralising place prompts a view of informal carers as social actors, engaged in sustaining place actions within the nexus of interactions with other people, organisations and society. By recognising the importance of place, an appreciation of how external factors arbitrate "the social processes and power relations which interpenetrate peoples' lives" is consequently enabled (Dyck, 1995: 308).

In summary, this section demonstrated that within *'Sustaining Place'*, the concept of place is an existential phenomenon, experienced and interpreted in interactions across the multiple aspects of the life-world (and related contexts) within which informal carers and persons with dementia are situated. The next two sections will explore how within the theory of *'Sustaining Place'*, the importance of place is also related to a perception of situated belonging, which is threatened when informal carers of persons with dementia encounter the problem of *'Living on the fringes'*.

10.4 Having a place - belonging

> "Human experience is not isolated ... it demonstrates a powerful representation or unity of meaning of belongingness and interconnectedness to the whole human condition" (Ray, 1994: 124).

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[54] See also Feld and Basso (1996), Becker (2003), McHugh (2003), Milligan (2003), Wiles (2005), Crooks (2007), Keogh and McGettrick (2008) and Wiersma (2008).

In the theory of *'Sustaining Place'*, a sense of belonging is important because it is fundamental to an appreciation of having a valued place. This is because perceiving one belongs is essential for informal carers to experience sustained connection with their life-worlds and the people, organisations and society encountered within them. The data in this study demonstrate that a sense of belonging is also essential for informal carers to sustain continuity with their pre-caring, current and future lives, in the midst of ongoing change to their place and that of the person with dementia. This section will therefore consider the importance of belonging and its connection to the concept of place in the problem of *'Living on the fringes'* and the theory of *'Sustaining Place'*. As will be seen, belonging is conceptualised as both a human necessity and a right in the context of this theory. It is within the context of interactions, or interruptions to interactions, that informal carers appreciate a sense of belonging or increasing alienation from their known life-worlds. Therefore, in working to sustain their place and that of the person with dementia, in the theory of *'Sustaining Place'* informal carers are simultaneously working to sustain the right to belong.[55]

The need to belong is a well regarded phenomenon. For example in gerontological nursing, Nolan et al (2004: 49) identify belonging, or "to feel part of things", as a key dimension of the 'Senses Framework' approach to relationship centred care, which includes the informal carer, older person and professional carer. Belonging is also a well recognised interest in a number of other health-related fields including: the humanities, social sciences, mental health and psychology. Croucher (2004) advocates an understanding of belonging in terms of attachment and identity, viewing these concepts as dynamic. However, the data in this study suggest that while a component of self-identity, a perception of belonging is located within and between informal carers' life-worlds within the theory of *'Sustaining Place'*. While comparable with some aspects of the previous writings on the subject of belonging, the emphasis on belonging in this theory is consequently less localised within the person of the informal carer. Rather, it is the socially constructed and experienced nature of belonging that is of concern in *'Sustaining Place'*. The theory suggests that a sense of belonging is an important pre-requisite to a positive interpretation of the meaning of living with dementia and is consequently also important to a positive experience of place. This is particularly demonstrated in the actions inherent in *'sustained self'* (*'Sustained place')*, which are: *'cherishing connection'*, *'being realistic'*, *'being recognised'* and *'positive contacting'*.

Similarly, Hagerty et al (1992: 172) in their analysis of the concept, propose that a 'sense of belonging' is "the experience of personal involvement in a system or environment so that

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[55] This nature of this working will be considered in more detail in Section 10.5.

persons feel themselves to be an integral part of that system or environment". These writers identify two dimensions of belonging. Firstly, valued involvement, whereby one feels valued, accepted and needed. Secondly, a perception of fit or congruence, for example with other people or environments through shared features (Hagerty et al, 1992). Of central concern in this study, is that *'Sustaining Place'* suggests that both valued involvement and informal carers' fit with their social environments are frequently disrupted in the presence of dementia. This was illustrated in the second component of the theory, *'Threatened place'*, and in particular in the context of *'shrinking world'* and *'experiencing marginalisation'*. In consequence, informal carers' sense of belonging begins to be compromised, if not eroded. Also, *'changing personal and social identity'* demonstrates that the informal care-related progressive changes to informal carers' social, occupational and other roles may progressively inhibit their ability to socially participate and inter-relate with others. These disruptions to valued involvement and social fit are concerning because Hagerty et al (1992: 173) note that a sense of belonging is an important aspect of connection to "people, places and things". Equally concerning is that Baumeister and Leary (1995), in their general exploration of the hypothesis that a need to belong is basic human motivation, connect a lack of belonging to potential psychopathology, as will be seen later in this section.

In this study, encountering the problem of *'Living on the fringes'* consequently appears to lead informal carers to an awareness of progressively lessening involvement, or at the very least changes to their involvement in aspects of their life-worlds. It simultaneously raises the same concerns for informal carers in relation to the person with dementia. This is compounded when informal carers become increasingly cognisant of alterations to familiar ways of interacting with social contexts and contacts in *'whittling to core'* and *'becoming a lesser person'* (*'Threatened place'*). It is also experienced when informal carers are required to interact with new dementia-related contexts in which they can perceive they are marginalised or dis-respected. An example of such identified by participants in this study, was interactions with various health and social care systems and particularly interactions with non-dementia specific services. This is demonstrated in *'negative health and social care contacting'* (*'Threatened Place')*. In essence, these experiences, and the meanings conveyed in them, can result in a growing perception of loss of and for some persons not belonging. Therefore *'Threatened place',* the second component of *'Sustaining Place'*, in particular brings the importance of belonging and its connection to place into stark focus. This supports an emergent experience of disconnection for informal carers. The sense of disconnection appears to gather momentum in tandem with the clinical progression of dementia and others' actions or reactions to or in its presence. It is further compounded within *'no idea whatsoever'* (*'Threatened place'),* in which informal carers are unsure what dementia implies for their individual lives.

Infringements to the experience of belonging and place consequently raise significant concerns in relation to the ability of informal carers, and potentially persons with dementia, to create and sustain social relationships and participation. The theory of *'Sustaining Place'* also stimulates disquiet about how informal carers and persons with dementia are positioned and treated by others, which can either improve or exacerbate the problem of *'Living on the fringes'*.[56] Therefore, in the presence of dementia, the data suggest that social connectedness can be compromised. For example, *'whittling to core'* and *'encountering other people's lessening reactions' ('Threatened place')* vividly illustrate the negative ways in which some known and unknown others may interact with informal carers and persons with dementia that can disrupt social connections. Social connectedness can be understood as the inter-relation of a person with other persons, the community and/or environment, which provide reassurance, commonality and contentment (Townsend and McWhirter, 2005; Buckley and McCarthy, 2009). The finding of a disruption to social connectedness is concerning in this study because Lee and Robbins (1998) equate social connectedness with belonging. These writers further emphasise that having a perception of connectedness equips people with a "social lens with which to perceive the world in which they live" (Lee and Robbin 1998: 338).

Increasingly, both connectedness and social isolation are attracting growing interest as potential health modifiers (Haun, Rittman and Sberna, 2008; Leal Hill, 2009). Innes (2009) in particular, highlights the importance of a sense of belonging to social inclusion in the field of dementia. The prioritisation of social inclusion represents a shift to promoting well-being, particularly in community care contexts, and as such human rights, social inclusion and community caring capacity building are pivotal to the future development of care (Philips, 2007). Barnes (2006) also suggests that to value caring as a component of social relating, will benefit not only the givers and receivers of care but also societal well-being more generally. However, where this is not the case and belonging is in question, the theory of *'Sustaining Place'* suggests that the experience of disconnection and social isolation can be injurious if not shattering to place. In addition, the informal carers interviewed in this study explicate a number of negative affective consequences arising out of *'Threatened place'*, including: sadness, anger and guilt, as participant CFM07 conveyed: *"That's right, I mean even if they [health professionals] asked the carer or the wife ... what's relevant to his [participant's husband with dementia] lifestyle, and judge the damn questions from that."* This finding is supported by Baumeister and Leary (1995), who highlight that negative affect occurs where relational bonds are interrupted or

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[56] This point will be explored in more depth in the following section.

rebuffed and Lee and Robbins (1995), who relate a lack of belongingness to the experience of loneliness.

Maslow (1954) importantly centralised belonging as a fundamental human need and motivation. More recently, Levett-Jones and Lathlean (2008) highlighted that as social beings, people need to belong and to experience acceptance and that this need is responsible for many of the pursuits, activities and thinking that people engage in. This supports informal carers' apparent valuing of the right to belong in this study and their simultaneous recognition that this right is frequently not upheld or enabled by society. In turn, this can lead to the need for informal carers to engage in *'Sustaining Place'* to protect themselves and the person with dementia from threats to place by securing a sense of belongingness. The conceptualisation of such actions in this study is again supported by Baumeister and Leary (1995), who suggest that people have an innate predisposition to construct a minimum number of enduring positive interpersonal relationships that are affirming for those involved. They further highlight that people tend towards resisting the undoing of established relational bonds (Baumeister and Leary, 1995). However, the theory of *'Sustaining Place'* goes a step further by perceiving actions to sustain place and belonging as more than innate tendencies. Therefore in this study, a consideration of the importance of belongingness provides enhanced understanding of the actions of informal carers throughout but particularly in the third component of the theory, which is *'Sustaining our place'*.

The identification of the centrality of belonging to place could also suggest a potential additional interpretation of some of the findings of the informal dementia care research reviewed earlier in Chapter 3. For example, research findings that suggest that the negative health impacts of informal caregiving may relate to informal carer burden might also be related to the effects of alterations to belonging and its impact on the perception of place. This potential connection warrants further investigation in future informal dementia care research. Interestingly, a sense of belonging and its relationship to health has previously been studied in fields other than dementia. For example, a review of the subject has suggested that deprivation of belonging is a fundamental cause of mental and physical health problems (Baumeister and Leary, 1995). More specifically, Hagerty and Williams (1999) examined the effect of sense of belonging (and other concepts) on depression and using path analysis found that sense of belonging was a more effective predictor of depression than social support. In a secondary analysis of a cross sectional design study, Sargent et al (2002: 121) suggested that "disruption in a person's relatedness can lead to biological, psychological and social disturbances", as the absence of a sense of belonging is linked to psychosocial distress. These researchers also demonstrated that a sense of belonging was related to psychosocial health and well-being and again that in some cases it buffered against the development of depression (Sargent et al, 2002).

The theory of *'Sustaining Place'* could also suggest an additional interpretive lens in relation to the dementia care research relating to the impact of social support on the experience of informal dementia care related stress. This research highlights the positive effects of social supports and networks (which can provide informational, emotional and practical supports) on informal dementia care induced stress (Connell, Janevic and Gallant, 2001; Cooke et al, 2001; Papastavrou et al, 2007). Considering the findings of my study, it could be hypothesised that a sense of belonging might also exert a positive effect in addition to the various subtypes of supports that might be experienced by informal carers from supportive others. This could signify an important difference in emphasis, when compared with some of the research reviewed in chapter three because it could suggest that belonging is of central importance to a more positive experience of informal dementia care. Somewhat similarly, Baumeister and Leary (1995) proposed that research indicating the stress reducing affects of social support might equally be accounted for by the belonging hypothesis, in that where sense of belonging is reduced or absent, this could account for stress. However, the volume of health-related belonging research conducted to date is limited and much of the writings draw on anecdotal accounts (Hagerty et al, 1992; Sargent et al, 2002). Therefore, while no significant conclusions can be drawn from this study, the phenomenon of belonging in relation to dementia and informal dementia care is clearly an area in need of further exploration.

In summary, while it is suggested that culture is orientated towards providing belongingness (Baumeister and Leary, 1995), the theory of *'Sustaining Place'* demonstrates that for informal carers, this cannot be taken as unproblematic in the presence of dementia. Croucher (2004) points to the current state of flux that is endemic in society and posits that belonging is a core component of such flux. As such, the concepts of belonging and place may have a wider applicability beyond the field of dementia. However, the focus of concern here is that specific affronts to belongingness can result in significant threats to the place of the informal carer and creates equal concerns on his/her part regarding the place of the person with dementia. The following section will examine two reasons that may help to explain why this occurs in this study.

10.5 Endangered place - affronts to place & belonging

The previous section demonstrated that the experience of a significant alteration to place is in most cases perceived by informal carers as negative and marginalising. Engagement in

'Sustaining Place' therefore occurs in the context of wanting to be, but not being able or enabled to fully immerse oneself, in the known life-world to the same degree or in the same ways as before dementia. The data suggest that this relates to the problem of *'Living on the fringes'* and the related impediments to informal carers' abilities to inter-relate with various aspects of their life-worlds. This section will examine two social affronts to inter-relatedness that were recognised as particularly salient during the conceptualisation of this problem and the theory of *'Sustaining Place'*. To this end, the impact and consequences of: (1) understandings derived from dementia discourses and (2) dementia-related stigma will be considered in relation to this study. It is suggested that both of these contribute to a compromised sense of place and belonging for informal carers and that informal carers perceive that they do the same for persons with dementia. In compromising place and belonging, it will be shown that these issues underpin informal carers' actions throughout the theory of *'Sustaining Place'*. Similar to Edwards and Imrie's (2003: 240) position in relation to disability, this section will therefore demonstrate that for informal carers, living with dementia is "influenced, and often compromised, by broader social and structural relations". This is because informal care is experienced in and constructed through interactions (Sevenhuijsen, 2000; Garey et al, 2002; O'Connor, 2007; Philips, 2007). Therefore from a social constructionist perspective, it is through relationships that the world becomes what it is to us (Gergen, 2009).

According to Askham et al (2007), home-life is suggestive of habituation, regularity and stability. However, the theory of *'Sustaining Place'* supports the contention that the experienced reality of dementia is intrusive to the regularities in informal carers' life-worlds because the experiences recounted by carers illustrate disruption to multiple facets of their home, work and social lives. In addition, the alien nature of the health and social care systems that informal carers have to increasingly interact with add to this disruption. Because of these disruptions, informal carers and persons with dementia encounter inter-relational alterations to their pre-caring or pre-dementia lives. In the first instance, these alterations contribute to the first component of the theory, *'Unsettled place'*, and continue into *'Threatened place'*, implying that informal carers become familiar with living with uncertainty. This is because informal carers' ontological equilibrium is disturbed as the sense of order and compliance with normalising cultural ideologies is disrupted (Becker, 1997). It is also because those who live with dementia, including informal carers, actively interpret, create and sustain the nature of their lives in relations with others (Bond and Corner, 2001; Askham et al, 2007; Philips, 2007). However, the presence of dementia, and people's reactions to it, can result in alterations to the behaviour [of all concerned] and the erosion of communication and relationships, adding to the potential isolation of the informal caring role (Perry, 2002; Mittleman, 2003; National Alliance for Caregiving, 2008). The isolation experienced by informal carers in this study is conceptualised within the context of *'shrinking world' ('Threatened place')*. In order to deepen understanding of the need for and constituents of *'Sustaining Place'*, it is necessary to explore why all of the above might occur. To this end, the first affront to place and belonging considered is the impact and consequences of understandings derived from different constructions of dementia on informal carers' social lives.

The theory of *'Sustaining Place'* demonstrates that different dementia discourses provide alternative ways of constructing the reality of dementia and they contribute to the positioning of people in particular ways in of inter-relating. For example, the demographic discourse constructs dementia and those with a diagnosis of dementia as a 'real' problem that is potentially cataclysmic to society both in terms of its personal and fiscal impacts. A number of other dementia discourses were considered earlier in this thesis, including: dementia as an age related process, a medically sanctioned disease, a feared process and an inter-relational experience. Foucault (1972, 1976) illustrates how people are situated within such discursive contexts that support certain knowledge forms, from which arise different social truisms. Each [dementia] discourse is consequently constructed to present a certain version of the world and aims to marginalise competing versions (Miller, 2008). Discourses are therefore mechanisms of power, referred to by Foucault (1980: 31) as "regimes of truth". For example, in contemporary western society, cognitive capacity can tend to be regarded as an essential feature of an individual's existence (Post, 2000a; Cantley and Bowes, 2004). Foucault's (1979) concept of 'normalising judgment' explains how people are judged by others in relation to such socially constructed standards of normalcy. Within biomedical and legal dementia discourses, standards for normal brain structure and cognitive functioning are agreed and officially sanctioned. However, in the presence of dementia these may not be attainable. Those persons not meeting the prescribed standards for competence and autonomous capacity can then be subjected to exclusionary actions.

This study suggests that exclusionary actions can also be experienced by those informal carers closest to persons with dementia. Instances of such exclusionary and marginalising actions were repeatedly described by participants. For example, CFM13 and her husband with dementia vividly described being repeatedly disregarded when: trying to convey a non-dementia related health concern to their general practitioner, when unable to have flexibility in terms of social outings (having to take the same walk over and over with a social carer) and being offered a fire alarm for their house as a suitable support from a community based nurse. The data also repeatedly suggest that the impact and consequences of biomedical dementia discourses contribute to *'experiencing health and social care system marginalisation'*. This is because the experiences recounted by informal carers demonstrate that consistent with Powell's (2009) assertion, professionals who primarily draw on medical dementia discourse to inform their practice can create persons as objects of health and social care. This discourse then creates subjectivities, in this case persons with dementia and informal carers, who can be perceived by health and social care professionals as 'docile bodies' (Foucault, 1979). Such persons can then be positioned and acted upon by medicine and its allied disciplines through the technical apparatuses of the clinical gaze (Foucault, 1973; Hyde, Lohan and McDonnell, 2004). These technical apparatuses are mechanisms that seek to position people in ways that they can be controlled and subjected to the disciplinary practices of the medical system, for example assessment and monitoring procedures.

While it is possible to present dementia discourses as discrete constructions, it is overly simplistic to suggest that within *'Sustaining Place'* any one discourse is a singular influence on people's reactions to and in the presence of dementia. This is because as discourses are socially constructed, they are also dynamic and historically situated (Clare, 2002; Carpentier et al, 2008). It is also because they exist and are sustained within and among other discourses (Hardin, 2001). This was demonstrated in Chapter 2, where examples of how dementia-discourses may inter-relate were identified. Similarly in *'Sustaining Place'*, various belief systems derived from different constructions of dementia influence understandings of: the nature of dementia, its causes and potential threats. For example, informal carers referred to their and other people's understanding of dementia in terms of being feared (lay discourse), while also explaining their understanding in terms of dementia as a disease (biomedical explanations). Formal care providers' narratives also frequently moved between multiple discourses when explaining dementia and the professionals' experiences in the field. As such, professionals referred to dementia in terms of: a disease located in brain pathology, as a disability and as a bio-psycho-social experience. Understanding of dementia is consequently eclectic and different social actors move between various constructions (Downs, Clare and Mackenzie, 2006). Similarly, O'Connor et al (2007: 132) acknowledge the availability of "multiple and competing [dementia] discourses or storylines … through which one can make sense of the world". The current study highlights the importance of appreciating the varied nature and impact of understandings derived from dementia-related representations. This is because different ways of understanding dementia can affect interactions between those who live with dementia and the social worlds in which they interact (Martorell Poveda, 2003; Kruse and Schmitt, 2006).

While the dementia-related understandings held by an individual are frequently eclectic, it is also evident in this study that certain constructions of dementia are positioned and sanctioned by some social groupings as more powerful than others. Of concern here, is that this is also critical to the problem of *'Living on the fringes'* and the theory of *'Sustaining Place'*. This is demonstrated in *'experiencing abandonment' ('Threatened place)*, where informal carers interpreted the withdrawal of known others as a consequence of the negative associations connected with dementia. It is also inherent in *'negative health and social care contacting' ('Threatened place')*, in which the impact of the professional understanding of dementia is primarily encountered. These sub-components support the contention that some understandings of dementia, arising out of shared socio-cultural meanings, can result in negative and/or inhumane actions towards those who live with dementia. While Kitwood (1997) would refer to such actions as manifestations of malignant social psychology that infringe the personhood of the person with dementia, they are interpreted in a different manner here. In this study, rather than being restricted to the personhood of the person with dementia, such actions are also understood to negatively impact on the informal carer. This is because this study suggests that those discourses that can result in inter-relational impacts can contribute to a compromised sense of place and belonging for both.

Sargent et al (2002) suggest that social stigma can particularly affect belonging. Instances of such stigma were poignantly referred to by informal carers in this study, For example, one informal carer described how her mother's neighbours avoided visiting because they didn't understand what was wrong [CFM10] and another referred to people's ignorance as a cause of abandonment [CFM15]. CFM16 also referred to being asked by her local shopkeeper not to send her husband who had dementia into his shop anymore, interpreting this as a further disconnection from a social context integral to both her and her husband's lives. The theory therefore illustrates the potential for those living with dementia, both informal carers and persons with dementia, to experience 'otherness' in the presence of affronts to place. Otherness has been recognised as a component of disability and mental health difficulties, in which persons are defined by difference that is perceived by others as threatening (Bracken, 2003; Edwards and Imrie, 2003; Hyde, Lohan and McDonnell, 2004). One reason for this is that those responsible for social control operate procedures to evaluate others, so that people can be assigned class membership, for example: ill, well, normal and abnormal (Smith, 1990). Clearly, dementia is an evaluative and interactive experience, wherein meaning is created through language and within the context of social interaction (Downs, Clare and Mackenzie, 2006). According to Goffman (1963), a person's social identity is usually established and perpetuated through socially constructed and agreed attributes that signify who the person is. Both the problem of *'Living on the fringes'* and the components of the theory of *'Sustaining Place'* suggest that social identity can be negatively affected in the presence of dementia. Disempowerment and social exclusion are consequently facets of life for persons with dementia, who can be constructed as different, undesirable and/or stigmatised (Cantley and Bowes, 2004;

Corner, Brittain and Bond, 2007). Importantly, social stigmatisation also applies to informal carers in this study. This is the second affront to place and belonging that is suggested as contributing to the need for informal carers to engage in *'Sustaining Place'*.

Although the word 'stigma' was recognised to be a professionally applied term early in this study, informal carers, and many of the professionals interviewed, generally identified with its components and consequences. These included: being labelled and subject to stereotyping, the associated negative dementia-related imagery, social isolation, marginalisation and the encountering of structural discrimination in the context of health and social care systems (Nolan et al, 2006).[57] The theory of *'Sustaining Place'* consequently demonstrates that dementia can be associated with differing degrees of social acceptability (experienced in *'sustained self'*) and unacceptability (experienced in *"Unsettled place'* and *'Threatened place'*) by those encountered in the context of various aspects of the life-world. This finding is not surprising. The stigma that is attached to mental ill-health is widely acknowledged (Brunton, 1997; Link et al, 1999; Byrne, 2000; Corrigan et al, 2005), as is dementia-related stigma (Benbow and Reynolds, 2000; Morgan et al, 2002; Iliffe et al, 2005; Katsuno, 2005; Downs, Clare and Mackenzie, 2006; Innes, 2009). Clearly, while bio-medical discourse suggests that dementia is value free, this is not the case in society, where stigmatising and pejorative meanings are attached to dementia (Pollitt, 1994). In addition, dementia-related stigma can be compounded by what Scholl and Sabat (2008) refer to as age-related stereotype threat. This was highlighted by informal carers and dementia care professionals in this study, who referred to ageing and dementia as a *"double whammy"* [AHPDO7] and a *"dual stigma"* [AHPDO8] that can lead to *"being very ostracised ... by society"* [AHPDO7]. Similarly, Brooker (2004) coins the term 'dementia-ism' to refer to the ageism directed towards those with cognitive impairment.

In his elucidation of stigma, Goffman (1963) explained the mismatch that can occur where actual social identities do not concur with anticipated social identities. When it emerges that someone possesses an undesired attribute (in this case dementia), this can result in the person being discredited socially. In contrast, those conforming to anticipated expectations are viewed and treated as 'normals' (in this study, those who are not closely affected by dementia). Similarly, Miles (1981) perceives stigma as the singling out of particular unwanted attributes that devalue the possessor and Jones et al (1984) view stigma as the holding of a mark indicative of deviance or flaw. Stigma is consequently a relational experience because social identity is influenced through inter-relating with socially constructed categorisations and those who are influenced by them (Goffman, 1963; Yang et al, 2007). These descriptions of stigma

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[57] Structural discrimination is defined by Yang et al (2007: 1525) as "institutional practices that disadvantage stigmatised groups".

correspond with many of the inter-relational experiences referred to by informal carers in this study and described in the preceding sections. Therefore, in experiencing the problem of *'Living on the fringes'* and in engaging in *'Sustaining Place'*, it is clear that informal carers, as well as persons with dementia, are subject to the components and consequences of stigma. Such direct experiences of stigmatising processes are described by Scambler (2009) as 'enacted stigma'.

However, much of the literature only emphasises the social exclusion and marginalisation of the person with dementia in this regard. For example, Cantley and Bowes (2004) recognise that dementia stereotypes can create a perception of social incompetence that functions at the inter-personal level, resulting in limitations in interactions with persons with dementia. In contrast, *'Unsettled place'* and *'Threatened place'* suggest that in accompanying the person with dementia, informal carers are frequently subjected to similar or related experiences. This phenomenon has previously been referred to as 'courtesy stigma' (Goffman, 1963), 'stigma by association' and 'family stigma' (Blum, 1991; MacRae, 1999; Ashencaen Crabtree and Chong, 2000; Ostman and Kjellin, 2002; Angermeyer, Schulze and Dietrich, 2003; Chang and Horrocks, 2006; Scambler, 2009; Werner, Goldstein and Buchbinder, 2010). Thus, where a person is linked to another perceived as stigmatised, society can treat both persons to some degree as the same and he/she is then "obliged to share some of the discredit" (Goffman, 1963: 43). As such, the theory of *'Sustaining Place'* makes an important contribution to the existing literature. This is because there is limited dementia-specific research involving this form of stigma and that which does exist is in many cases culturally specific (MacRae, 1999; Werner, Goldstein and Buchbinder, 2010).

While early representations of stigma localised the issue within the person who was discredited or discreditable (Goffman, 1963), more recent perspectives have moved the locus of concern outward to stigma perceived as a socio-cultural process. It is this perspective that in particular informed my understanding of stigma in this study. For example, Link and Phelan (2001) conceptualise stigma as a process involving the co-occurrence of its components: labelling, stereotyping, separation, status loss and discrimination in the presence of power.[58] These theorists also recognise that stigma impacts on numerous domains of a person's life, which is consistent with informal carers in this study who experienced disruptions to place and belonging in the context of: familial, social, occupational and health and social care system contexts. This confirms that it is the experiences encountered within and between various aspects of informal carers' life-worlds, and the people, organisations and society encountered within them, that must be explored to comprehensively understand how informal carers address the problem of

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[58] Other contemporary writers on the subject include Crocker, Major and Steele (1998) and Scambler (2009).

'Living on the fringes'. Yang et al (2007: 1527) refer to the adoption of such an orientation as "the felt flow of engagements in a local world". The position advocated by these writers was particularly helpful in conceptualising my understanding of the mechanisms underpinning the need for informal carers to engage in '*Sustaining Place*' work.

Yang et al (2007: 1524, 1528) suggest moral experience as an "interpretive lens by which to understand the behaviours of ... the stigmatised [informal carers and persons with dementia] and stigmatisers, for it allows an examination of both as living with regard to what really matters and what is threatened" in the context of "a local social world". Importantly, ascertaining and acting on what matters to others is identified by Sevenhuijsen (2003) as an aspect of active citizenship. Thus, having been theoretically sensitised to the importance of moral experience and using CGT, it was possible for me to conceptualise the importance of place and its sustenance to informal carers. Using moral experience as an interpretive frame then enabled my appreciation of the potential reasons for affronts to place and belonging herein. This is because according to Yang et al (2007: 1528), the actions of those who are understood to stigmatise others can be understood as practical or functional responses to "perceived threats, real dangers and fear of the unknown". Using this interpretive lens suggests that in the case of my study, those who stigmatise informal carers and persons with dementia may do so as a consequence of the negative understandings inherent in some of the dominant dementia discourses explored earlier. For example, *'experiencing abandonment'*, referred to earlier in this chapter, can then be understood as withdrawal of family, friends, colleagues or other social contacts, as a result of dementia-related fear and/or threat. Therefore, while frequently referred to separately, it is suggested that understanding arising out of certain dementia discourses and dementia-related stigma are inter-related.

This section discussed two social affronts to belonging and place that were identified in the course of this study. These were the impacts and consequences of (1) understandings derived from dementia discourses and (2) dementia-related stigma. The following section will consider how the theory of *'Sustaining Place'* accounts for the ways in which informal carers challenge the resultant disconnection experienced where they perceive that place and belonging are compromised. Rather than accepting affronts to place as a fait accompli, it is suggested that *'Threatened place'* acts as a stimulus to action on the part of informal carers and that the actions taken are directed towards the sustenance of place and belonging. In so doing, it is proposed that this is resonant of what Foucault describes as a discourse that has arisen as an alternative to the dominant discourses of dementia, which negatively position those who live with dementia. The productive and inter-relational nature of such power will be demonstrated by constructing informal carers as social actors, who in engaging in *'Sustaining Place'* are simultaneously exercising their agency.

10.6 'Sustaining Place' - challenging disconnection, enabling citizenship

It is clear from the preceding sections that informal carers of persons with dementia are frequently subject to difficult interaction experiences. It is also evident that the theory of *'Sustaining Place'* demonstrates that informal carers act on behalf of themselves and persons with dementia, in response to such experiences within and across various aspects of their life-worlds. Having recognised a definitive sense of *'Threatened place'*, the nature of these informal carer actions is illustrated in particular within the third and fourth theoretical categories of *'Sustaining our place'* and *'Sustained place'*. The actions contained within these categories are supported by informal carers' narratives, which vividly convey the nature of their attempts to create, sustain and maximise positive inter-relational connections so as to sustain place. The theory demonstrates that this occurs despite the increasing difficulties associated with doing so over the progressive course of dementia. Therefore, I consider that the theory of *'Sustaining Place'* advances understanding when considered in relation to some of the previous research that confirms reducing social networks and spaces but does not probe deeper. For example, some previous empirical work tends to note informal caring induced social restrictions, in most instances without seeking to ascertain if informal carers are doing anything about this. This could be interpreted to imply that informal carers are passive and acted on by the various systems they encounter. As a consequence, informal carers' actions when experiencing inter-relational challenges, beyond the immediate care-giving situation, are not comprehensively understood. This section will consequently demonstrate how the theory of *'Sustaining Place'* addresses this deficit. It will consider the manner in which *'Sustaining Place'* demonstrates why and how informal carers are working to sustain their place and that of persons with dementia. In so doing, it is suggested that *'Sustaining Place'* offers a new perspective by explaining the processes by which informal carers challenge the disconnection and infringements to citizenship experienced in the context of *'Living on the fringes'*.

In light of the previous discussion of the impact of various discursively produced social constructions of dementia and informal dementia care, use of the terms 'informal carer' and 'informal care' could be suggested to passively position or devalue those who care for persons with dementia. The choice of an appropriate term was consequently a particular concern when I was exploring an appropriate title for those to whom this theory refers. It was also a concern because in recognising the importance of the various discursive constructions of dementia and informal dementia care, I wanted to advance new understanding without any overdue influence from any particular existing position unless it demonstrated relevance. The term 'informal carer' is accepted to be contentious (Adams, 2008). However, while alternatives were considered (including: carer, caregiver, lay or family carer and significant other), I considered them equally contentious because each also connotes certain socially constructed meanings and associations. The choice of an appropriate term was also complicated, in that during interview informal carers did not refer to themselves in terms of any one the particular titles from those identified above; although in deciding to participate they did identify themselves as carers when completing the reply slip. In the end, while recognising that other terms could be used, I chose to use 'informal care' and 'informal carer' for their familiarity within the context in which the study was conducted. However, I concur with Chappell and Parmenter (2005) who contend that there is nothing informal about such care but that use of the term is justified to discriminate between care provision by relatives and friends and that by health and social care personnel. It was with this intent that I adopted the terms 'informal care' and 'informal carer' in this thesis and not to passively position such carers in the context of the theory. Instead it is acknowledged that in Foucauldian terms, within the theory of *'Sustaining Place'* informal carers experience and resist power. They do so by establishing themselves as active social agents, constructing an alternative subjectivity to the more passive constructions of informal dementia care referred to earlier. This is explicitly identified in the presentation of the theory. Therefore, in engaging in *'Sustaining Place'*, it is suggested that informal carers are, as highlighted by Burkitt (2008), looking outward to actively form social selves.

While the previous section suggested that informal carers, and persons with dementia, are constructed as 'docile bodies' and powerless in the face of the oppressive effects of certain dominant dementia discourses, Foucault's later works illustrate that power is relational. This is because where power is exercised the possibility for resistance is also present (Faubian, 2002; Mills, 2004; Miller, 2008). Power therefore resides within all social relations and is productive in contrast to oppressive (Hyde, Lohan and McDonnell, 2004). Thus, Foucault (1980: 82) argued for the magnification of excluded or marginalised subjectivities, as he considered that "it is through the reappearance of this knowledge, of these local, popular knowledges that criticism performs its work". Therefore, the theory produced in this study advances understanding because it conceptualises the localised knowledge and experiences of informal carers who were earlier shown to experience marginalisation in the context of *'Threatened place'*. By providing an interpretive lens, Foucauldian concepts enabled me to comprehend how informal carers experience and manage the impact and consequences of understandings arising from different dementia discourses within interactions in the context of various aspects of their life-worlds.

Drawing on this lens, I was able to conceptualise informal carers' sustaining place work as a means of resisting the socio-relational consequences of dominant dementia discourses, whose effects were previously shown to threaten place and marginalise informal carers.

For example, Foucault's elucidation of the ethical self was assistive in this regard. The construction of the ethical self stems from Foucault's (1985, 1990) last works on the history of sexuality. This work moves beyond the explicit resistance of power to a consideration of the formation of the self as an ethical endeavour within the context of relations of power (Flaming, 2006; Miller, 2008). The ethical self suggests that individuals, as social agents, can consider how they are positioned through dominant discourses and via reflection choose to create a more desirable socially constructed self from the available discursive positions (Burkitt, 2008; Miller, 2008). According to Flaming (2006: 221), in doing so people can construct themselves in particular ways because they can free themselves from "inhibiting, normalizing or dominating discourses". The theory of *'Sustaining Place'* suggests that in the case of informal dementia care, this is accomplished through carers primarily positioning themselves within and acting out of an inter-relational understanding of dementia. For example, this discourse explains informal carers' actions in relation to *'joining the informal network' ('Sustaining our place')* and in *'sustaining others' ('Sustained place')*. It does so by suggesting that these actions are directed towards creating and maintaining a sense of belonging and place, in that informal carers are acting to ensure social connectivity by seeking out similar or supportive others. Such a position is supported by Baumeister and Leary (1995), who contend that membership of a group may satisfy the need to belong and that to some degree those to whom one belongs are interchangeable. This is important because these writers hypothesise that where social bonds are formed through adversity, as is the case in *'Sustaining Place'*, this lends particular credence to belonging. O'Connor (2007), drawing on positioning theory, also highlights that positioning oneself in terms of being a carer through identification with similar others, supports a sense of belonging and wider connection to community. In *'Sustaining our place'*, this leads to informal carer behaviours designed to maximise confirming encounters and to resist the (actual or potential) dehumanising effects of non-confirming or marginalising encounters. This is particularly evident within the context of *'protective enfolding' 'joining the informal network'* and *'constructing a positive support network' ('Sustaining our place').*

In this study, a further example of informal carers choosing to operate from an inter-relational discourse is their rejection of biomedical and lay constructions of dementia when their affects are experienced as exclusionary and impersonalising. Where this is encountered, *'Sustaining our place'* demonstrates how informal carers draw on certain enabling factors to facilitate *'nurturative protecting'* and *'inter-relational labouring'*. The five enabling factors identified to facilitate enhanced engagement in *'Sustaining our place'* were: *'knowing the person with dementia', 'perceiving caring as a moral way of being', 'developing expertise', 'having a frame of reference'* and *'strategising'*. Drawing on these factors suggests informal carers' intent is to re-inject humanity into interpersonal encounters. One way in which this is addressed, is where informal carers position themselves as valued contributors to inter-relational exchanges, for example with formal care providers when *'navigating the health and social care systems'*. Therefore, consistent with Sabat's (2001) position, the theory of *'Sustaining Place'* illustrates how informal carers work towards adopting a focus on positive positioning and well-being in their attempts to sustain place and belonging. In Foucauldian terms then, the categories of *'Sustaining our place'* and *'Sustained place'* could suggest an attempt by informal carers to destabilise dominant discourses, which construct them as passive subjectivities. In so doing, informal carers, drawing on an inter-relational understanding of dementia, position themselves as social actors working toward the sustenance of place. This hypothesis is supported by Miller (2008: 258), who highlights how social actors can purposefully position themselves in terms of certain discourses to "pursue their own interests" in contrast to being passively positioned by more dominant discourses.

The theory of *'Sustaining Place'* therefore demonstrates how informal carers work to try to ensure that their principal concerns remain visible and are acted upon within and across multiple aspects of their life-worlds. The theory further implies that informal carers perceive this as a right that out of necessity needs to be acted upon. Where informal carers recognise this need, the outcome of this study suggests that the components of *'Sustaining Place'* represent informal carers' attempts to challenge disconnection and uphold their citizenship rights and those of persons with dementia. As such, in engaging in *'Sustaining Place'*, and particularly in the theoretical components of *'Sustaining our place'* and *'Sustained place'*, informal carers can be understood to be engaging in a form of active citizenship. This would appear to be supported by Baldwin (2008b) and Perron, Rudge and Holmes (2010) who, although referring to persons with dementia and mental illness respectively, identify belonging and social relationships as central facets of citizenship. Baldwin (2008b: 232) consequently advocates for a combining of personal and policy narratives to enhance "social inclusion and the sense of self", so that "citizenship and self move closer together". In relation to informal caring, Barne's (2006) further suggests that despite a lack of recognition for such care as a form of citizenship within private domains, collectively informal carers are increasingly advocating for social justice by seeking acknowledgment and voice. He further highlights that this challenges a perception of health and social service users as "needy, dependent or lacking agency" (Barnes, 2006: 142). Herd and Harrington Myer (2002) also call for the recognition of informal care work as a form of civic engagement and social or participatory citizenship. In conceptualising informal carers as exercising their citizenship, the theory of *'Sustaining Place'* makes an important contribution to this debate. The theory also demonstrates that when *'sustaining others' ('Sustained place'),* informal carers are attempting to enable others' citizenship, while simultaneously exercising their own.

The importance of citizenship is increasingly recognised in relation to dementia (Marshall and Tibbs, 2006; Baldwin, 2008b; Barnes and Brannelly, 2008; Boyle, 2008). Bracken's (2003) definition particularly informs the understanding of citizenship adopted in this study in relation to informal carers. Citizenship from this perspective is understood:

> "to refer to someone who is allowed to, and feels able to, participate fully in the society in which he/she is a member ... someone who benefits from the rights and carries the responsibilities available to other members of that society ... being regarded as a full human being, entitled to expect the same from life and the society in which one finds oneself as everyone else. On a basic level it involves being free of discrimination, exclusion and oppression" (Bracken, 2003: 1-2).

Cantley and Bowes (2004) suggest that prioritising citizenship for persons with dementia necessitates a commitment to social inclusion. Innes (2009) also posits that the application of citizenship illustrates the recognition of dementia as an international phenomenon and offers the potential to amalgamate the macro and the micro in the analysis of dementia as a social experience. In relation to this study, this implies that understanding of informal dementia care as a social phenomenon, is advanced where citizenship is used to contextualise individual caring experience in the context of its organisational, institutional and societal influences. In recognising the limitations of personhood as being apolitical, Bartlett and O'Connor (2007) also advocate for a citizenship perspective as an important adjunct to dementia practice and research. They consider that doing so encourages consideration of the socio-political context of dementia. Similarly, Perron, Rudge and Homes (2010) suggest that citizenship calls to mind belonging, integration, security and partnership within the context of a socio-political community. However, similar to personhood, the concept of citizenship has to date most frequently been addressed in relation to persons with dementia. The theory of *'Sustaining Place'* extends this perspective by encouraging the opening up of a wider debate, in that the citizenship of the informal carer is also centralised.

Worryingly, Bracken and Thomas (2005) suggest that citizenship presents a challenge to professional expertise and position, and that professional resistance may consequently hinder its successful attainment. For example, in health and social care the need for a participatory approach between formal and informal carers and persons with dementia is officially acknowledged. However, Clarke (1999) points out that this is frequently compromised where there is superficial recognition of the concept, but the agenda is directed by one side. In this study, this was illustrated in *'negative health and social care contacting' ('Threatened place').* Here, the data demonstrate that despite health and social care policy espousing participatory working, informal carers' contribution is frequently undervalued, discounted or not sought, particularly by non-dementia specific formal carers. In contrast, where specialist dementia care professionals or understanding others are encountered, recognition of place and respect for the informal carer and person with dementia are frequently perceived. This was shown in *'being recognised'* and *'positive interacting' ('Sustained place').*

Bracken and Thomas (2005) highlight that citizenship is also a concern in dementia because the way in which the concept is commonly constructed, tends towards the marginalisation of those with cognitive impairment. Sayce (2000) similarly refers to the loss of citizenship that occurs where a person is labelled with a psychiatric diagnosis. This implies that citizenship is qualified (Bracken and Thomas, 2005). Importantly, the theory of *'Sustaining Place'* suggests that the marginalisation that results where cognition is impaired also applies to informal carers. This is because their citizenship is frequently infringed when experiencing the problem of *'Living on the fringes'*. *'Unsettled place'* and *'Threatened place'* illustrate that infringements to place are experienced across multiple aspects of informal carers' life-worlds and the people, organisations and society encountered within them. In contrast, Post (2000b: 31) calls for an ethics of inclusivity in dementia and refers to the need for equality in contrast to what he refers to as "dementist views and policies of convenient exclusion". However in emphasising inclusion, Bracken and Thomas (2005) wisely caution against conflating 'inclusion' with 'incorporation' wherein homogeneity is emphasised. If this were to occur, the place of those whose lives are touched by dementia could again be threatened, in that the individuality of each person's relationships within and across his/her life-world would be compromised and thus individual uniqueness would be disregarded. This would compound the need to engage in *'Sustaining Place'* in contrast to lessening or eliminating the need for it. Thus, Philips (2007) argues for a model of citizenship that celebrates and respects difference. Such an approach would emphasise inter-dependence, reciprocity in care and inter-relationality, which according to many seminal writers are not currently central societal values (Sevenhuijsen, 2003; Barnes, 2006; Barnes and Brannelly, 2008).

The analysis presented in this section contributes to a more positive understanding of the nature of informal dementia care. It does so by demonstrating that on the basis of socially derived understandings, informal carers employ the multiplicity of intricate social processes conceptualised in the third and fourth components of *'Sustaining Place'*. These actions are consistent with Burkitt's (2008: 3) emphasis on the construction of "social selves" and his contention that who a person is or can be, is influenced by politics, rights and duties constructed in society. As such, social relations are central to what it means to be a social self. The actions within the theoretical components of *'Sustaining Place'* are directed towards ensuring informal carers continued social participation and the recognition and sustenance of their place and that of persons with dementia. Therefore in this study, the concept of 'place' is fundamental to an appreciation of both the originating problem *('Living on the fringes')* and the theory, which describes informal carers' actions in response to this problem *('Sustaining Place')*. This theory demonstrates that the experiences and actions contained within the first two components of *'Sustaining Place'*, which are *'Unsettled place'* and *'Threatened place'*, lead to a patterned array of actions on the part of informal carers. Together, these actions constitute the third component of the theory, *'Sustaining our place'*. When engaging in these actions, informal carers' intent is to attain the fourth component of the theory, *'Sustained place'*, for themselves and persons with dementia.

10.7 In summary

This chapter discussed the theory of *'Sustaining Place'* in relation to a number of underpinning concepts and issues, including: the importance of place, belonging, endangered place, and finally in terms of challenging disconnection and enabling citizenship. While it was acknowledged that there is a significant body of pre-existing informal dementia care literature, it was suggested that this theory provides a new perspective. It does so by repositioning and expanding understanding in relation to some of this pre-existing work, for example: the impacts, consequences and temporal processes involved in informal caring, and explorations of the burdens and stresses of the role and ways of coping. By focusing on informal carers as social actors, it was shown that the use of the CGT methodology to inform the conduct of this study enabled the conceptualisation of informal carers' concerns and the social processes they engage in to address them. In so doing, the purpose of the study, which was to produce knowledge with which to build a conceptual understanding of living with dementia from the perspective of informal carers, has been addressed.

The substantive theory that has resulted was shown to represent an "account … that challenge[s] the taken-for-granted conventional understanding [of informal dementia care], and simultaneously invite[s] us into new worlds of meaning and action" (Gergen, 1999: 116). This is because *'Sustaining Place'* illuminates the embedded nature of informal dementia care. It does so by making clear that people cannot be separated from the social, cultural and political worlds, which constitute their experience and structures their interpretation of meaning and subsequent actions (Davies and Harre, 1990; Garey et al, 2002; Perron, Rudge and Holmes, 2010). This is a particular strength of the thesis, as social participation and integration are particular concerns in terms of ageing-related issues and informal care, both nationally (Department of the Taoiseach, 2006; Government of Ireland, 2007a, 2007b) and internationally (United Nations Programme on Ageing and The International Association of Gerontology and Geriatrics, 2007). The theory of *'Sustaining Place'* identifies the social domains within which informal dementia care is located and constructed. This theory also portrays informal carers as social agents who proactively engage in meaning-making. On the basis of the resultant understanding, informal carers then engage in actions directed towards addressing the problem of *'Living on the fringes'*, on behalf of themselves and persons with dementia.

This discussion also illustrated how persons with dementia and informal carers are frequently perceived and positioned in society with reference to the impacts of some of the most common dementia-related discourses. It was demonstrated that despite official policy and literature support for concepts including: personhood, citizenship, inclusion and connectedness for those whose lives are touched by dementia, the realities of living with dementia are, for some, far from consistent with the public rhetoric. As the theory of *'Sustaining Place'* confirms, attributes that can mark people as different, such as dementia, continue to result in a perception of difference and compromised status for informal carers and persons with dementia. Similar to Davies and Nolan (2008), this study consequently demonstrates the importance of inter-relationships (in this case with other people, organisations and society) to the social experience of living with dementia. This is because the undesirability of an illness affects those labelled with the diagnosis, informal carers and the attitudes and behaviours of people towards them (Estes and Binney, 1989). Significantly, it is suggested by a number of writers that ultimately this could result in social exclusion, marginalisation of the person with dementia (Gubrium, 1986; Corner and Bond, 2004), informal carers (Goffman, 1963) and in the extreme social death (Kleinman, 1988; Sweeting and Gilhooly, 1997).

The use of moral experience (Yang et al, 2007) as a sensitising lens in this study, was helpful in considering the mechanics of the stigmatising processes that contribute to informal carers experiencing the problem of *'Living on the fringes'*. This lens was also helpful in understanding informal carers' consequent actions within *'Sustaining Place'*. Drawing on moral experience, as a means to facilitate understanding, also supports the future need to explore the research phenomenon from the perspective of relevant others in order to gain a comprehensive understanding of how different social actors affect what matters most to informal carers. Innes (2009) similarly recognises that to advance current knowledge, the field of dementia studies must move beyond individualistic concerns to consider how social structures and processes impact on the experience of dementia. While the theory supports this recommendation, it also reinforces the essentiality of continuing to include the perspectives of those closest to the phenomenon of dementia, such as informal carers. Similarly, Bracken and Thomas (2005: 237) advocate for the need to "create a silence" within which the voices of those not usually heard can be appreciated.

The discussion further illustrated that for participants in this study, informal care is primarily problem focused. As such, informal carer actions were shown to be directed towards what matters most to carers, in this case to be recognised and respected as persons with a valued place in relation to their life-worlds. This concern was also shown to extend to the person with dementia. It was suggested that related actions equate to a form of "citizen practice" (Perron, Rudge, and Holmes, 2010: 103) enacted by informal carers in the context of interactions within the social body. To date, informal dementia care research has tended to focus on particularistic perspectives, insufficiently accounting for how wider social influences affect the experience of dementia (Bartlett and O'Connor, 2007). Such reductive modes of research have primarily viewed informal care as negative, burdensome and/or stressful. However, the theory conceptualised in this study, constructs informal dementia care as a varied experience that while difficult is also satisfying, particularly so where *'Sustained place'* is attained. Therefore, the theory of *'Sustaining Place'* makes a contribution to the existing research that illustrates the rewards and gratifications inherent in informal dementia care. This is not to infer that many aspects of the overall experience are not difficult. In contrast, it is clear from participant narratives, and the literature, that while *'Sustaining Place'* work is likely to be satisfying when successful, it is simultaneously taxing. This is particularly so where *'Sustained place'* is not reached. However, actions directed towards the sustenance of place within this theory, and in particular within *'nurturative protecting'* and *'inter-relational labouring' ('Sustaining our place')*, are considered important endeavours by informal carers. As such, they are a focusing orientation within the meleis of shifting sands inherent in living with dementia.

The theory of *'Sustaining Place'* is therefore presented as a robust theoretical conceptualisation of the social phenomenon that is informal dementia care. Consistent with the CGT approach, this theory is grounded in both the substantive field of informal dementia care and in wider related theory. *'Sustaining Place'* is suggested to be the first theory to conceptualise the intricate actions involved in sustaining place across multiple aspects of an informal carer's life-world in the context of progressive dementia. Further, in presenting an additional understanding of informal dementia care to those currently available, *'Sustaining Place'* encourages readers to question their own understandings of, and actions in the presence of, dementia. The theory also stimulates questioning of how such understandings and actions might affect what matters most to informal carers in this study, that is their place and that of persons with dementia.

Chapter 11 ‘Sustaining Place’: Situational and Quality Considerations, Implications and Recommendations

11.1 Introduction

Post (2001: S17) “calls for a focused and attentive listening to the voices of family caregivers”, as one means to direct the agenda in the field of dementia. He also argues for humility on the part of researchers in terms of their interactions with the “constituency”, whom he suggests should dictate the research questions in contrast to the academy. The use of the CGT approach adopted in this study dovetailed well with this intent because it set out to identify, name and conceptualise social patterns arising out of the experiences of informal carers of persons with dementia. The theory of ‘Sustaining Place” is consequently offered as a heuristic to enable understanding of the problem of ‘Living on the fringes’ and the processes engaged in by informal carers’ to sustain their, and where possible the person with dementia’s, places in their life-worlds. To conclude the thesis, this chapter will address the following:

11.2 Situational considerations,
11.3 Quality considerations,
11.4 General implications of the theory of ‘Sustaining Place’,
11.5 Implications and recommendations for policy,
11.6 Implications and recommendations for dementia care practice and
11.7 Implications and recommendations for research.

11.2 Situational considerations

As research is always subject to situational factors, the conduct, findings, quality considerations, implications and recommendations of this study need to be interpreted with reference to the following:

- The data collection process was limited to interviews with participants recruited through the auspices of the Alzheimer Society of Ireland. It is possible that informal carers not accessing the supports and services of the Society might engage in different and/or additional actions to resolve their concerns. Theoretically sampling such carers might have enabled the generation of additional categories to integrate into the theory of ‘Sustaining Place’. This is a consideration for future modification of the theory.
- Researcher influence on participants during the collection of data needs to be considered. This is because it became apparent that by being present and listening to carers’ experiences, I became part of the process of ‘Sustaining Place’. The participants

may have perceived their participation and constructed their narratives as components of sustaining their and the person with dementia's places. This reiterates the lack of value neutrality inherent in this type of research, while simultaneously supporting the socially constructed nature of the research outcome.

- The majority of the data were derived from single interviews with participants. Conducting more than one interview over time and/or the addition of another form of data collection, for example observation, might have yielded additional categories.
- The theory of 'Sustaining Place' is derived from and relates to informal dementia care. To enhance its applicability to other care contexts, and to begin to raise the theory from a substantive to a formal grounded theory, theoretical sampling with other types of informal carers would be required.[59] An example of such a group would include informal carers of persons with various chronic illnesses and of various ages.
- 'Sustaining Place' was constructed in a particular cultural and temporal context. Readers should be cognisant that constructions of informal carers' concerns and related social processes could change with time and place. This implies the importance of considering the contextual situatedness of this research and the theory itself.
- As interviews were the primary method of data collection, I cannot attest that the descriptions of actions given occurred in the manner recounted by participants. The sensitivity of the research topic and the potential to reveal intimate information to someone who could be regarded as an outsider, may have affected participants' narratives. However, this should not be overstressed because making sense of social experience often occurs in retrospect and as per the canons of social constructionism, interpretations can be reconstructed over time.
- Theoretical saturation, in terms of an individual study, is a matter of subjective interpretation. It was considered that theoretical saturation was achieved in the current research. However, it is not definitively known if further data collection would have produced alternative accounts. Consistent with CGT, had this occurred these would have been incorporated into the conceptualised structure. This demonstrates the unfixed and modifiable nature of the theory.

11.3 Quality considerations

"Trying to get it right, while looking in from the outside" (Morse, 2009: 579).

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[59] A formal grounded theory is defined as "a theory of a SGT [substantive grounded theory] core category's general implications, using, as widely as possible, other data and studies in the same substantive area and in other substantive areas" (Glaser, 2007: 99).

A CGT study can be appraised by considering the entirety of the research process and the way in which the components of CGT impact on the quality of the research (Elliott and Lazenbatt, 2005). According to Anfara, Brown and Mangione (2002: 29), "good naturalistic inquiry shows the hand and opens the mind of the investigator to his or her reader". The emphasis is not solely on post-hoc judgements of quality. It is also on procedural credibility during the operationalisation of the process (Glaser and Strauss, 1967; Glaser, 2003). This is necessary to demonstrate the robustness of the methodology and how it furthers knowledge (Tobin and Begley, 2004). CGT is generated through engagement with its methodological components and results in conceptual abstraction to produce a parsimonious theory, of probability statements, elucidating a latent pattern of behaviour in a substantive area (Glaser, 2003). The methodology produces theory based on modifiable conceptualisation of concepts that relate to each other, not accurate factual description of a fixed immutable truth (Glaser, 2003; Lomborg and Kirkevold, 2003). Post theory testing or verification of the hypothesised relationships between concepts is not the purpose of the approach. Therefore, attempts to impose non-CGT quality criteria demonstrate a misunderstanding of the methodology. Criteria used to judge the credibility of other methodologies (for example, validity and reliability used in primarily quantitative research or those identified by Sandelowski (1986, 1993) for qualitative research) are not applicable when making quality claims about the CGT research process or its outcome. Instead, CGT has its own criteria (Glaser and Strauss, 1967; Glaser 1978), which were used as guides in this study (Table 11.1).

Table 11.1 Criteria used to address quality

- **Fit** – the theoretical categories should fit the data and not be derived from or chosen to support pre-existing theoretical perspectives
- **Work** – the theory needs to provide a pragmatic organisation of data, which explains the substantive area to which it pertains, i.e. it should explain, predict or interpret what is happening
- **Relevance** – the theory should be general enough to be applied in varied daily contexts
- **Modifiability** – the theory is modifiable in light of conditional changes and/or the acquisition of further data

11.3.1 Fit

The extent to which a CGT matches the situation in the social context being studied is referred to as 'fit' (Lomborg and Kirkevold, 2003). In terms of this criterion, I took Glaser's (1978) advice to constantly refit the concepts and categories to the data throughout the constant comparative analysis. As concepts began to emerge, they were theoretically sampled for in the existing data, through further data collection and later in the literature to ensure that they patterned out. This process of refitting was vital to ensure that a concept name was appropriate to the data it was held to refer to. Later in the process, as categories were constructed, the same process was continued. The concurrent nature of CGT procedures consequently involved continuous checking to ensure that concepts were upheld. This also minimised conjecture or personal biases on my part. Where negative cases were discovered, they were not discarded. Instead, they generated more questions for onward theoretical sampling and opened up additional vistas of enquiry. The identification of incidents that do not necessarily fit with the emergent pattern is important to ensure that a theory is adapted to incorporate variation (Corbin and Strauss, 2008). For example, in 'Sustaining Place', it became clear that some informal carers may not reach 'Sustained place' and the theory was adapted to account for this. As the core category of 'Sustaining our place' was identified, concepts and categories were again checked to ensure continued fit. In some cases, this necessitated the renaming of existing concepts as the emergent social pattern developed (Chapter 5, Table 5.2). The criterion of fit was also facilitated by my immersion in the data and my concentration on generating concepts from it. This ensured that the theoretical hypotheses are grounded in the data, having emerged from the systematic processes of: constant comparison, theoretical sampling and memoing.

As the categorical relationships and their properties grew, they were continually integrated into the overall theoretical structure, to densify the theory, until the categorical structure was saturated (Chapter 5, Section 5.10.5). The consideration of alternative hypotheses or explanations for what was happening in the data also ensured I did not take data at face value. This would have resulted in a superficial poorly integrated outcome with little practical application. The details of these processes are demonstrated in the descriptions of how I used the tools of CGT (Chapter 5). My intent in presenting these accounts is to provide a "linking process" so that readers can reach their own conclusions in terms of the theory's fit (Glaser and Strauss, 1967: 229). They also provide a decision trail recording my progression through the research process. Thus, they act as a record of the circumstances of the theory's production (Murphy et al, 1998; Chiovitti and Piran, 2003; Rolfe, 2006a). The inclusion of participant quotations in the presentation of the theory (Chapters 6 to 9) also supports the theoretical categorisations and their properties by acting as indicators of fit (Chiovitti and Piran, 2003).

However, it is impossible to provide explicit detail of how and why all decisions were made in the course of this study. This is because in CGT pre-conscious processing is vital to theory conceptualisation and consequently decisions may not always be easily articulated (Glaser, 1998).

As social reality is a product of human construction, it is not possible to "escape the social world in order to study it" (Hammersley and Atkinson, 1995: 17). Rennie (1998a, 1998b) views CGT as an innovation in this regard, as it incorporates the subjectivity and reflexivity of subject and researcher. There is a resultant onus on the researcher to demonstrate through reflexivity how his/her presence and assumptions influenced the research process and outcome (Murphy et al, 1998; Horsburgh, 2003). The detail provided in this thesis is an account of my subjective presence in so far as it was known to me (Freshwater, 2005). In providing descriptions of my actions, the creative, reflexive and self-critiquing nature of CGT is illustrated to enable appraisal of the criterion of 'fit'. While it may appear that reflexivity was a post-hoc occurrence, the opposite is the case because reflexivity was critical to my ongoing engagement with the CGT methodology. For example, as my skill with CGT increased, the important influence of dementia-related discourses emerged as a factor in the experiences of participants and myself. It became clear that participants' narratives reflected many of the dementia related discourses outlined in chapter two and that these influenced their meaning-making and linked actions. This led me to examine my own assumptions, particularly as I was a nurse and familiar with the professional discourses. Acknowledging my assumptions, led me to appreciate how operating solely within my professional understandings could have biased my perceptions and limited the potential vistas of understanding and thus the theory's fit and quality. This is an example of how reflexivity can shape the research outcome through consideration of the politics of location and positioning, which are considered so important by Koch and Harrington (1998).

To augment my reflexivity, peer debriefing, where the research supervisory team acted as critical friends, was also employed. This stimulated "consideration and exploration of additional perspectives and explanations at various stages…of data collection and analysis" (Long and Johnson, 2000: 34). Peer debriefing also contributed to the development of my theoretical sensitivity, which is referred to by Dey (2004: 92) as the "drawing on a wider range of literature, perspectives and experience to inform the analytic encounter with data".

11.3.2 Work

If a CGT is to fulfil the criterion of 'work', the reader must consider that it is applicable and meaningful to those concerned (Glaser, 1998). The adoption of a systematic approach to the research process ensured that the theory of 'Sustaining Place' works. This is because its components fit the social reality of informal carers of persons with dementia and therefore it has saliency in terms of its explanation of variations in the behaviours engaged in by them. The theory is also salient to those who may use it to understand the meaning and experiences of informal care, for example health and social care professionals. The criterion of 'work' is further illustrated when the degree of theoretical integration is considered. However, two points are noteworthy in relation to the workability of the theory. Firstly, the theory is presented as one possible representation of the informal carers' actions, as I concur with Hammersley's (1992) position that knowledge is never certain and other perspectives on this phenomenon could be possible. Secondly, as this theory relates to a particular context, no claims are made regarding its utility in terms of other substantive areas of dementia and non-dementia related informal care. To do so, would require further theory development.

11.3.3 Relevance

Relevance is important to quality in CGT because it enables the surfacing and conceptualisation of what matters to informal carers, avoiding the imposition of "pet concepts of schools of thought" (Glaser, 1998: 237). This implies that a CGT should make known what was previously hidden and that the resultant conceptualisation should be useful to those whose circumstances it purports to address. The relevance of 'Sustaining Place' is demonstrated in a number of ways. Firstly, the participants' main concern was allowed to emerge during the research process. Consequently, the basic social process conceptualised is relevant to the actual lives of informal carers of persons with dementia. Secondly, participants' and not professionals' concerns were central to the research process. This is illustrated as the study began with the intent to study stigma related to dementia. As previously demonstrated (Chapter 5, Section 5.10.4), this terminology was quickly identified as professionally imposed because whereas stigma contributed to informal carers' main concern, it was not their main concern. Instead, adherence to the methods of CGT enabled the conceptualisation of the latent basic social process of 'Sustaining Place", relevant to the social worlds of the informal carers in the study. To have let the professional concern drive the research endeavour would have destabilised the relevance of the theory and thus its fit (Glaser, 2003). Thirdly, received concepts were not imposed from pre-existing theories. These are frequently conjectured, not conceptualised, and may not have fit the data (Glaser, 1998). Instead, where existing theories were drawn on, they earned their relevance if they demonstrated a good fit.

Over the course of its development, I explored the components of the theory and the story of its evolution with various carers and professionals knowledgeable in dementia, through discussion and by presenting at a number of specialist conferences (Appendix 22). This was an opportunity to 'test the waters' to see how potential users perceived its relevance. In so doing, I recognised that it would not be possible for another person to identify exactly with each theoretical component. This is because while participant narratives were co-constructed, the theory is also individual in that the analytic conceptualisation was subject to my interpretation (Daly, 1997). However those carers that spoke with me, told me that the theory of 'Sustaining Place' captured their experiences in a way they had previously found difficult to articulate. While they could describe what they did in the day-to-day sense of caring, the wider aspects of their experiences were more difficult to put into words. These carers welcomed the concepts within the theory as a way to give voice to what informal dementia care entails when in the presence of other people, organisations and society. Those professionals who provided feedback on some of the theoretical concepts, also commented on the evocative power of these and the theory's potential ability to broaden understanding of informal dementia care. During the course of its development, the theory was therefore perceived as an advance on existing explanations of informal dementia care. This is because 'Sustaining Place' portrays how dementia affects the wider totality of informal carers' lives. As one carer, when I explained a little about what I had found said: *"... you have it! That is it. It is not my mother, it is other people that I have trouble with"*.

11.3.4 Modifiability

"Generation is an ever modifying process and nothing is sacred if ... giving priority to the data" (Glaser, 1978: 5). Nothing exists on its own. It usually flows from what came before and will be superseded by what will follow. Therefore, the criterion of modifiability is essential to a rigorous CGT, if it is to fit, work and be relevant. The modification of a CGT is the continuous enhancement of both its plausibility and applicability, so that it explains the major variations in behaviour in the substantive area in question (Glaser, 1992, 2003). The theory of 'Sustaining Place' has been modified during its construction (through constant comparison and ongoing theoretical sampling) to explain emergent differences in the data. Future modification or recasting in the light of new data is a continuous possibility. The possibility of modification to accommodate change over time is consequently vital to the continued utility of the theory of 'Sustaining Place'.

The detail presented throughout this thesis can be used by readers to make a judgement as to the quality of its outcome. Ultimately such judgements must rest with the reader. This is because despite decades of debate about how best to judge the quality of a diverse range of naturalistic research approaches, resulting in a crisis of representation, consensus remains elusive (Emden and Sandelowski, 1998; Whittemore, Chase and Mandle, 2001; Sandelowski, 2006). While evaluative criteria devised for CGT are assistive, I do not view them as absolute. This is because both their meaning and use can change over time and between researchers and readers. Also, as each study and each reading of it is to a degree unique, any appraisal of quality must be subject to the judgment of the reader (Sandelowski and Barroso, 2002; Rolfe, 2006a, 2006b). Thus, decisions regarding the quality of this study depend on the value systems of participants, researcher and appraiser and their operational contexts (Horsburgh, 2003). This is particularly so if one understands the social world as constantly reconstituted and therefore truth as similarly constructed and reconstructed (MacDonald and Schreiber, 2001). The criteria of fit, work, relevance and modifiability do retain utility in such a world, as they enable appraisal in the absence of unitary truth by recognising the dynamic status of social reality (MacDonald and Schreiber, 2001; Lomborg and Kirkevold, 2003). This implies that if 'Sustaining Place' is judged to fit, work and have relevance, then it can be appraised to exist not in terms of being immutable but in a locally constructed context, time and place.

11.4 General implications of the theory of 'Sustaining Place'

The implications of this theory primarily arise from the meanings and actions attributed to dementia experiences by carers of persons with dementia. The theory suggests that a single pronged approach is unlikely to improve the lives of informal carers and persons with dementia to any great degree. This is because the social arenas in which people are situated are varied and the levels within them many. However, in presenting 'Sustaining Place', the individuality of dementia experience is acknowledged, while also allowing for "unity ... in diversity" (Gubrium, 1986: 156). In addition, conceptualising this CGT with reference to a social constructionist lens, offers the potential to promote "a better way of thinking and, more important, living with respect to the worlds we inhabit" (Weinberg, 2008: 15). Existing dementia research has tended to separate caring perspectives (for example: informal, formal and policy perspectives). While recent work has emphasised triadic approaches to formal care provision that include the informal carer (Fortinsky, 2001; Davies and Nolan, 2008; Ryan et al, 2008), there is still a need to build on this work using a wider lens. To this end, future research will need to combine and importantly expand the variant perspectives of all social actors and identify connections and disconnections between and among them. This will provide a depth of understanding that to date has not been available.

The theory of 'Sustaining Place' begins this process from the perspective of the informal carer by elucidating inter-relations and processes between the carer and other persons, structures and systems encountered in the course of informal care for persons with dementia. The theory thus demonstrates saliency in terms of the realities of living with dementia. Both Gubrium (1995) and Jones (2006) advocate for such a turn, to the direct experience and related situations found within the local discourses provided by informal carers. The identification of the problem of 'Living on the fringes' and the conceptualisation of 'Sustaining Place' support a need to consider the meaning and nature of social connectedness, social inclusion and citizenship for informal carers of and persons with dementia. They are also a means by which to identify realistic ways in which a sense of place and belonging may be supported. The theory further suggests that some informal carers who attain 'Sustained place' engage in raising awareness and sustaining work with other informal carers of and persons with dementia. Consequently, there is an opportunity to develop interventions to equip such persons with enhanced skills to engage in related activities.

The outcome of this study also implies a continued need to achieve change with respect to how dementia is regarded throughout society. While such change will not occur quickly, the identification of effective means of attaining lasting change will be fundamental to addressing the problem of 'Living on the fringes'. To this end, interventions are required to enhance societal understanding of dementia and to encourage the surfacing and recognition of negative public attitudes to dementia and those whose lives are touched by it. Public education and information programmes will need to highlight dementia-related fear and stigma, challenge stereotypes and address the prejudice, discrimination and marginalisation that can be experienced by informal carers of and persons with dementia. However, as no single intervention is likely to affect widespread and lasting societal change, a variety of age, ethnic, gender and generation specific interventions are required. For example, a review of the literature and the findings of the funded report on which this study was built, suggests the following may be beneficial: targeted education, sustained and meaningful contact with those whose lives are touched by dementia, media campaigns and legislative, advocacy and human rights approaches (Nolan et al, 2006).

In summary, 'Sustaining Place' clearly demonstrates that impediments to a sustained sense of place and structural barriers encountered by persons whose lives are touched by dementia, need to be tackled. The theory provides a robust basis on which to identify and recommend policy, health and social care practice and research developments. The recommendations that now follow are derived from the real worlds of dementia-related life experiences. Therefore, they have the potential to make a meaningful difference by meeting the actual needs of informal carers of persons with dementia, in contrast to conjectured needs imposed upon them.

11.5 Implications and recommendations for policy

This study highlights a pressing need to address policy for informal carers of and persons with dementia. The current Irish Action Plan for Dementia (O'Shea and O'Reilly, 1999) was devised over ten years ago and to date its recommendations have not been fully implemented. Updating existing policy will increase the likelihood that in line with other jurisdictions[60], persons with dementia and informal carers are supported with policy that is relevant and has regard to the current and future needs of those it serves. The theory of 'Sustaining Place' further supports an imperative to incorporate the expert knowledge possessed by those whose lives are touched by dementia in designing effective health and social care policies. Other researchers have identified a similar need, calling for the intermingling of lay and professional epistemologies (Keady et al, 2007).

It is therefore recommended that:

1. Dementia must be regarded as a priority in terms of Irish policy development and implementation.

2. A participatory approach to dementia and informal carer policy formulation is adopted, inclusive of informal carers, persons with dementia and other relevant stakeholders.

3. The National Carers' Strategy should be published as a matter of urgency to signal the societal valuing and recognition of the place of informal carers within Irish society.

4. Policies directed towards informal carers and persons with dementia need to promote choice, meaningful and appropriate social inclusion and citizenship at macro, meso and micro system and societal levels.

5. Sufficient resources (including: human, financial, educational and informational) are provided to support the implementation of policies for informal carers and persons with dementia.

6. The Irish dementia and informal care advocacy movements be strengthened in order to provide a mechanism to support and lobby for and with those whose lives are touched by dementia.

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[60] See for example, Living Well with Dementia. A National Strategy (Department of Health, 2009).

11.6 Implications and recommendations for dementia care practice

The theory of 'Sustaining Place' demonstrates a need for health and social care system and practice developments designed to decrease the problem of 'Living on the fringes' and support the 'Sustaining Place' work of informal carers. This theory thus provides a basis on which to plan and implement interventions that can link policy and service delivery interventions aimed towards meeting the needs of service users. However, as the recommendations outlined below are inter-sectoral and will take time, resources and potentially infrastructural development, change is likely to be incremental in nature. In relation to informal carers, formal interventions that enable the development of coping skills and to surface an awareness of the discourses that inform their understandings and actions may be of benefit. For example, those informal carers that fear dementia may experience a greater sense of threat to their sense of place, particularly if dementia is understood as a source of shame. In contrast, an understanding of dementia as an inter-relational experience could lessen the experience of 'Threatened place'.

With regard to the health and social care system difficulties identified, including the disconnection and fragmentation reported in the course of the study, a culture of inclusiveness and acceptance is required in service planning and delivery. There is also a need for recognition that health and social care services, and the ways in which they work, are alien to many persons who encounter them. The theory of 'Sustaining Place' further illustrates that this is only compounded when marginalisation and inflexibility are experienced by informal carers. Similarly, Doherty et al (2009: 503) refer to the dementia service user journey as "uncharted territory – [with] no A-Z or road atlas". Currently because of this, much of the learning that occurs for informal carers within formal care services (and the wider social and occupational aspects of their lives) is trial and error in nature (Huckle, 1994). The theory suggests a consequent need to enhance informal carer skills to enable negotiation of formal systems and to balance the requirements of instrumental caring with the requirements of 'Sustaining Place'. Formal care services must also learn to do better. For example, they need to be more responsive to the needs of informal carers and persons with dementia as they move through these systems over the progressive course of dementia. The potent influence of appreciating service user stories to the development of services and professional education has previously been acknowledged (Doherty et al, 2009). This is further supported by the narratives of participants in this study, which highlight the need for formal care providers to listen and attend to the perspective of informal carers' as service users.

The theory of 'Sustaining Place' offers a means for professionals to enhance this aspect of their role. This is because the theory can be used to improve formal dementia care with individuals, in addition to enhancing broader service planning and delivery. For example, the theoretical structure could be used as a heuristic to position an individual informal carer in relation to a theoretical component or components, as part of a person-centred approach to the provision of supports. In so doing, professional understanding of the current experiences and needs of the informal carer, and potentially the person with dementia, could be enhanced. The knowledge gained could then be used as a basis to identify and implement appropriate supports and formal care services. However, the expertise of informal carers would need to be recognised to facilitate such an approach, as would their role as active members of health and/or social care teams. This is an issue of concern in 'Sustaining Place' because many informal carers' experiences suggest that this is currently not the case. In particular, the importance of assessment and the central place of informal carers within this process need to be acknowledged. This is the case particularly with dementia progression, as persons with dementia may have increasing difficulty in communicating their perspectives and informal carers' needs may change.

It is therefore recommended that:

1. In light of the finding that informal carer actions within 'Sustaining Place' are both self and person with dementia centred, formal care interventions should be oriented towards the specific needs of the informal carer-person with dementia dyad and the individual needs located within this dyad.

2. Tailored interventions to meet the needs of informal carers should be developed based on their position in relation to the four components of 'Sustaining Place'.

3. The unique epistemological expertise of informal carers should be sought, valued and utilised to inform service planning and person-centred care delivery.

4. Informal carers, where appropriate and ethical (particularly where dementia is advancing), are involved in the ongoing assessment of and care planning with and for the person with dementia.

5. Informal carers should receive a person-centred and ongoing assessment of their own needs similar to that legislated for in the United Kingdom.

6. Transparent referral pathways are developed to enhance the journey of the informal carer and person with dementia through the health and social care systems.

7. A review of the formal dementia care systems is conducted to identify ways to:
    a) enhance communication and collaboration within and between services,
    b) develop flexible, seamless systems of care that where possible facilitate choice and
    c) ensure that dignity and respect are upheld to ensure due regard for the place of the informal carer and person with dementia within formal care systems.

8. Interventions should be devised to strengthen informal carer abilities in relation to the enabling factors that underpin 'Sustaining our place' (Chapter 8, Section 8.4). For example, surfacing awareness of these factors and exploring ways to use them.

9. In light of the importance of peer and formal supports to the sustenance of place, that existing formal and voluntary models of support, in which informal carers can create alliances with similar others, are strengthened and expanded.

10. There is a need to identify ways in which health and social care professionals can support sustaining place work, so as to ameliorate the problem of 'Living on the fringes'.

11. There is a need to resource and develop a case manager or key worker role to work with informal carers and persons with dementia from the time of diagnosis, so as to provide information, guidance and individualised support on a case by case basis.

12. Professional education should be structured to enhance understanding of the nature and impact of dementia discourses and how they influence practitioner assumptions and actions in relation to informal carers and persons with dementia.

13. Professional education programmes should equip practitioners with the requisite knowledge and skill sets to respond to the individual and complex needs of informal carers and persons with dementia.

14. Service and practice innovations are evaluated in terms of whether they achieve their specified aims. Evaluation is also required to ascertain the degree to which they improve or address the problem of 'Living on the fringes' and enable the achievement of 'Sustained place'.

11.7 Implications and recommendations for research

While the theory of 'Sustaining Place' has elucidated a previously un-explored aspect of informal dementia care, the findings of this study support the need for continued research in a number of interconnected areas. For example, consistent with the CGT criterion of modifiability (Section 11.3.4), there is scope for ongoing development of the theory. It is also clear that future research agendas should be set in partnership with those whose lives are most closely touched by dementia, in this case informal carers. This would potentially increase research relevance and maximise the potential for meaningful findings with which to enhance understanding and improve the experience of living with dementia. The current study suggests that the dynamics of inter-relations between people change in the presence of dementia and that the reasons for and mechanisms of such change need to be better understood from a multiplicity of perspectives. Thus, the perspectives of persons other than informal carers need to be explored in relation to 'Sustaining Place', including: persons with dementia, formal care providers, family and other social network members.

It is therefore recommended that:

1. The theory of 'Sustaining Place' could be further developed:
    a. by involving informal carers of persons with dementia not in contact with or using the services of the Alzheimer Society of Ireland,
    b. through the addition of other data collection methods, for example through observation of actual interactions between informal carers, persons with dementia and others which could uncover additional concepts to include in the theory and
    c. through replication in other jurisdictions, 'Sustaining Place' could be developed to accommodate potential gender, cultural and/or geographic variations in people's perceptions of and actions in the presence of dementia.

2. Future research should explore potential ways to amplify the properties of 'Sustained place', which are: 'sustained self' and 'sustaining others'.

3. In order to raise the theory of 'Sustaining Place' to a formal grounded theory, its appropriateness to other areas of informal care should be investigated by theoretically sampling those who provide informal care for persons with other chronic and/or life limiting conditions.

4. Research is needed to identify meaningful ways in which to support ongoing social connectivity, inclusion and citizenship for informal carers of persons with dementia:
    a. over the course of dementia and
    b. across the continuum of care.

5. As the theory of 'Sustaining Place' relates to the perspective of the primary informal carer, future research could be conducted to conceptualise the processes engaged in to sustain place by:
    a. persons with dementia,
    b. couples, where one person is diagnosed with dementia and
    c. family units affected by dementia.[61]

6. The components of 'Sustaining Place' be investigated from the perspective of health and social care professionals, with a particular emphasis on actual and potential system and professional contributions to 'Threatened place' and ways of addressing them.

7. Research is conducted to explore the impact and consequences of the dementia discourses that non-caregiving social network members and the public primarily draw on to inform their understandings and actions in relation to dementia.

11.8 In conclusion

While research to date has explored various components of the multiple facets of informal dementia care, it has not yet provided a comprehensive conceptualisation of informal caring in the context of the social domains in which it occurs. This is the crux of what 'Sustaining Place' begins to address and the niche into which the theory fits. 'Sustaining Place' demonstrates that the complexity of dementia can be appreciated by turning to the socially constructed nature of the experience and how this can affect the meaning and experience of dementia for informal carers (and others). Thus, using the CGT methodology facilitated participants to portray their subjective selves in inter-relation to the social worlds around them. This has added a new perspective to what is already known about informal dementia care, by avoiding a conceptualisation of the phenomenon that is solely localised to either the related intra-psychic or instrumental aspects of the experience. It does so not by negating previous ways of knowing,

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[61] Consideration would need to be given to the diverse nature of contemporary family structures in the conduct of any such research.

but by formulating an additional perspective that has inherent regard for the contribution of what has gone before. The theory of ‘Sustaining Place’ is therefore a conceptualisation of the phenomenon of informal dementia care that illustrates a new way of understanding the realities of living with dementia. It does so by conceptualising the informal carer experience as one that involves: the social construction of meaning, interpretation and actions directed towards addressing the problem of ‘Living on the fringes’ through engagement in the components of ‘Sustaining Place’.

References

Ablon, J. (2002) The nature of stigma and medical conditions. Epilepsy and Behaviour 3 (6S2): 2-9.

Acton, G. and Kang, J. (2001) Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. Research in Nursing and Health 24 (5): 349-360.

Adams, T. (1996) Informal family caregiving to older people with dementia: research priorities for community psychiatric nursing. Journal of Advanced Nursing 24 (4): 703-710.

Adams, T. (1998) The discursive construction of dementia care: implications for mental health nursing. Journal of Advanced Nursing 28 (3): 614-621.

Adams, T. (1999) Developing partnership in dementia care: a discursive model of practice In: Adams, T. and Clarke, C. Dementia Care. Developing Partnerships in Practice London: Bailliere Tindall.

Adams, T. (2000) The discursive construction of identity by community psychiatric nurses and family members caring for people with dementia. Journal of Advanced Nursing 32 (4): 791-798.

Adams, T. (2002) The construction of identity in the accounts of informal carers for people with dementia. Education and Ageing 17 (2 & 3): 237-255.

Adams, T. (2008) Dementia Care Nursing. Promoting Well-being in People wtih Dementia and their Families. Basingstoke: Palgrave Macmillan.

Adams, T. and Clarke, C. (1999) Dementia Care: Developing Partnerships in Practice. London: Bailliere Tindall.

Algase, D. (2007) Editorial: nursing science and dementia care. Western Journal of Nursing Research 29 (8): 939-943.

Almberg, B., Grafstrom, M., Krichbaum, K. and Winbald, B. (2000) The interplay of institution and family caregiving: relations between patient hassles, nursing home hassles and caregivers burnout. International Journal of Geriatric Psychiatry 15 (10): 931-939.

Almberg, B., Grafstrom, M. and Winbald, B. (1997a) Caring for a demented elderly person - burden and burnout among caregiving relatives. Journal of Advanced Nursing 25 (1): 109-116.

Almberg, B., Grafstrom, M. and Winbald, B. (1997b) Major strain and coping strategies as reported by family members who care for aged demented relatives. Journal of Advanced Nursing 26 (4): 663-691.

Almberg, B., Jansson, W., Grafstrom, M. and Winbald, B. (1998) Differences between and within genders in caregiving strain: A comparison between caregivers of demented and non-caregivers of non-demented elderly people. Journal of Advanced Nursing 28 (4): 849-858.

Alvesson, M. and Skoldberg, K. (2000) Reflexive Methodology. London: Sage Publications.

Alzheimer Europe. (2006) Who Cares? The State of Dementia Care in Europe (online). AlzheimerEurope.Available:http://www.alzheimer-europe.org/upload/SPTUNFUYGGOM/downloads/BAF644C16E7D.pdf (17th December 2008).

Alzheimer Society of Ireland. (2006) Dementia Manifesto, 2007-2009. Dublin: Alzheimer Society or Ireland.

Alzheimer Society of Ireland (2009a) Irish Statistics (online). Alzheimer Society of Ireland. Available:http://www.alzheimer.ie/eng/Media-Centre/Facts-About-Dementia/Irish-Statistics (24th November 2009).

Alzheimer Society of Ireland (2009b) Media Guidelines on Use of Language in Dementia (online). Alzheimer Society of Ireland. Available: http://www.alzheimer.ie/eng/Media-Centre/Guidelines-to-Dementia Language (23rd October 2009).

American Psychiatric Association (1994) Diagnostic and Statistical Manual of Mental Disorders. Washington DC: American Psychiatric Association.

An Bord Altranais (2000) Scope of Nursing and Midwifery Practice Framework. Dublin: An Bord Altranais.

An Bord Altranais (2007) Guidance to Nurses and Midwives Regarding Ethical Conduct of Nursing and Midwifery Research. Dublin: An Bord Altranais.

Andren, S. and Elmstahl, S. (2005) Family caregiver's subjective experiences of satisfaction in dementia care: aspects of burden, subjective health and sense of coherence. Scandinavian Journal of Caring Sciences 19 (2): 157-168.

Andren, S. and Elmstahl, S. (2008) The relationship between caregiver burden, caregiver's perceived health and their sense of coherence in caring for elders with dementia. Journal of Clinical Nursing 17 (6): 790-799.

Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S.H. and Whitlach, C. (1995) Profiles in Caregiving. The Unexpected Career. San Diego: Academic Press.

Anfara, V., Brown, K. and Mangione, T. (2002) Qualitative analysis on stage: making the research process more public. Educational Researcher 31 (7): 28-38.

Angermeyer, M., Schulze, B. and Dietrich, S. (2003) 'Courtesy stigma': a focus group study of relatives of schizophrenia patients. Social Psychiatry and Psychiatric Epidemiology 38 (10): 593-602.

Annells, M. (1996) Grounded theory method: philosophical perspectives, paradigm of inquiry, and postmodernism. Qualitative Health Research 6 (3): 379-393.

Annells, M. (1997a) Grounded theory method, part I: within the five moments of qualitative research. Nursing Inquiry 4 (2): 120-129.

Annells, M. (1997b) Grounded theory method, part II: options for users of the method. Nursing Inquiry 4 (3): 176-180

Appleton, J. and King, L. (1997) Constructivism: A naturalistic methodology for nursing inquiry. Advances in Nursing Science 20 (2): 13-22.

Arai, A., Matsumoto, T., Ikeda, M. and Arai, Y. (2007) Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? International Journal of Geriatric Psychiatry 22 (12): 1255-1261.

Arksey, H. and Glendinning, C. (2007) Choice in the context of informal care-giving. Health and Social Care in the Community 15 (2): 165-175.

Armstrong, D. (1983) The Political Anatomy of the Body: Medical Knowledge in the Twentieth Century. Cambridge: Cambridge University Press.

Arno, P., Levine, C. and Memmott, M. (1999) The economic value of informal caregiving. Health Affairs 18 (2): 182-188.

Ashencaen Crabtree, S. and Chong, G. (2000) Mental health citizenship in Malaysia. International Social Work 43 (2): 217-226.

Askham, J., Briggs, K., Norman, I. and Redfern, S. (2007) Care at home for people with dementia: as in a total institution? Ageing and Society 27 (1): 3-23.

Atkinson, P. and Hammersley, M. (1994) Ethnography and participant observation In: Denzin, N. and Lincoln, Y. (eds) Handbook of Qualitative Research. Thousand Oaks: Sage.

Baker, K. and Robertson, N. (2008) Coping with caring for someone with dementia: reviewing the literature about men. Aging and Mental Health 12 (4): 413-422.

Baldwin, C. (2008a) Toward a person-centred ethic in dementia care: doing right or being good? In: Downs, M. and Bowers, B. (eds) Excellence in Dementia Care. Research into Practice. Maidenhead: McGraw-Hill/Open University Press.

Baldwin, C. (2008b) Narrative (,) citizenship and dementia: the personal and the political. Journal of Aging Studies 22 (3): 222-228.

Baldwin, C. and Capstick, A. (2007) Tom Kitwood on Dementia. A Reader and Critical Commentary. Maidenhead: McGraw Hill.

Ballenger, J. (2006) Progress in the history of Alzheimer's disease: the importance of context. Journal of Alzheimer's Disease 9 (Supplement): 5-13.

Ballenger, J. (2008) Reframing dementia: the policy impliactions of changing concepts In: Downs, M. and Bowers, B. (eds) Excellence in Dementia Care. Research into Practices. Maidenhead: McGraw-Hill/Open University Press.

Barnes, M. (2006) Caring and Social Justice. Basingstoke: Palgrave Macmillan.

Barnes, M. and Brannelly, T. (2008) Achieving care and social justice for people with dementia. Nursing Ethics 15 (3): 384-395.

Bartlett, H. and Martin, W. (2002) Ethical issues in dementia care research In: Wilkinson, H. (ed) The Perspectives of People with Dementia. Research Methods and Motivation. London: Jessica Kingsley Publishers.

Bartlett, R. and O'Connor, D. (2007) From personhood to citizenship: broadening the lens for dementia practice and research. Journal of Aging Studies 21 (2): 107-118.

Baumeister, R. and Leary, M. (1995) The need to belong: desire for interpersonal attachments as a fundamental human motivation. Psychological Bulletin 117 (3): 497-529.

Beale, B., Cole, R., Hillege, S., MacMaster, R. and Nagy, S. (2004) Impact of in-depth interviews on the interviewer: rollercoaster ride. Nursing and Health Sciences 6 (2): 141-147.

Beard, R., Knauss, J. and Moyer, D. (2009) Managing disability and enjoying life: how we reframe dementia through personal narratives. Journal of Aging Studies 23 (4): 227-235.

Becker, G. (1997) Disrupted Lives. How People Create Meaning in a Chaotic World. Berkeley: University of California Press.

Becker, G. (2003) Meanings of place and disaplcement in three groups of older immigrants. Journal of Aging Studies 17 (2): 129-149.

Becker, P. (1993) Common pitfalls in published grounded theory research. Qualitative Health Research 3 (2): 254-260.

Bedard, M., Molloy, W.D., Squire, L., Dubois, S., Lever, J. and O'Donnell, M. (2001) The Zarit burden interview: a new short version and screening version. The Gerontologist 41 (5): 652-657.

Benbow, S. and Reynolds, D. (2000) Challenging the stigma of Alzheimer's disease. Hospital Medicine 61 (3): 174-177.

Benoliel, J. (1996) Grounded theory and nursing knowledge. Qualitative Health Research 6 (3): 406-428.

Benton, T. and Craib, I. (2001) Philosophy of Social Science. Basingstoke: Palgrave.

Berchtold, N.C. and Cotman, C.W. (1998) Evolution in the conceptualisation of dementia and Alzheimer's disease: Greco-Roman period to the 1960's. Neurobiology of Aging 19 (3): 173-189.

Berger, P. and Luckmann, T. (1966) The Social Construction of Reality. New York: Penguin Books.

Berr, C., Wancata, J. and Ritchie, K. (2005) Prevalence of dementia in the elderly in Europe. European Journal of Psychopharmacology. 15 (4): 463-471.

Berrios, G. (1994) Dementia and aging since the nineteenth century In: Huppert, F., Brayne, C. and O'Connor, D. (eds) Dementia and Normal Aging. Cambridge: Cambridge University Press.

Berrios, G. (2004) Dementia: historical overview In: Burns, A., O'Brien, J. and Ames, D. (eds) Dementia. 3rd Edition. London: Hodder Arnold.

Betts Adams, K. (2006) The transition to caregiving: the experience of family members embarking on the dementia caregiving career. Journal of Gerontological Social Work 47 (3/4): 3-29.

Betts Adams, K., McClendon, M. and Smyth, K. (2008) Personal losses and relationship quality in dementia caregiving. Dementia 7 (3): 301-319.

Bigus, O., Hadden, S.C. and Glaser, B. (1994) The study of basic social processes In: Glaser, B. (ed) More Grounded Theory Methodology: a Reader. Mill Valley CA: Sociology Press.

Billings, A.G. and Moos, R.H. (1984) Coping, stress, and social resources among adults with unipolar depression. Journal of Personality and Social Psychology. 46 (4): 877-891.

Blum, N.S. (1991) The management of stigma by Alzheimer family caregivers. Journal of Contemporary Ethnography 20 (3): 263-284.

Blumer, H. (1969) Symbolic Interactionism. Englewood Cliffs, New Jersey: Prentice-Hall.

Boller, F. and Forbes, M. (1998) History of dementia in history: an overview. Journal of Neurological Sciences 158 (2): 125-133.

Bond, J. (1992) The medicalization of dementia. Journal of Aging Studies 6 (4): 397-403.

Bond, J. (2001) 'Sociological perspectives' In: Cantley, C. (ed) A Handbook of Dementia Care. Buckingham: Oxford University Press.

Bond, J. and Corner, L. (2001) Researching dementia: are there unique methodological challenges for health services research? Ageing and Society 21 (1): 95-116.

Bond, J., Corner, L., Lilley, A. and Ellwood, C. (2002) Medicalisation of insight and caregiver's responses to risk in dementia. Dementia 1 (3): 313-328.

Borrayo, E., Goldwaser, G., Vacha-Haase, T. and Hepburn, K. (2007) An inquiry into Latino caregivers' experience caring for older adults with Alzheimer's disease and related dementias. Journal of Applied Gerontology 26 (5): 486-505.

Bosanquet, N. (2001) The socioeconomic impact of Alzheimer's Disease. International Journal of Geriatric Psychiatry 16 (3): 249-253.

Bowers, B. (1987) Intergenerational caregiving: adult caregivers and their aging parents. Advances in Nursing Science 9 (2): 20-31.

Boychuck Duchscher, J. and Morgan, D. (2004) Grounded theory: reflections on the emergence v's forcing debate. Journal of Advanced Nursing 48 (6): 605-612.

Boyle, G. (2008) The mental capacity act 2005: promoting the citizenship of people with dementia? Health and Social Care in the Community 16 (5): 529-537.

Bracken, P. (2003) Citizenship and Psychiatry. Inaugural Seminar of the Centre for Citizenship and Community Mental Health. University of Bradford: 1-17.

Bracken, P. and Thomas, P. (2005) Postpsychiatry. Mental Health in a Postmodern World. Oxford: Oxford University Press.

Bramble, N., Moyle, W. and McAllister, M. (2009) Seeking connection: family care experiences following long-term dementia care placement. Journal of Clinical Nursing 18 (22): 3118-3125.

Brannen, J. (1988) The study of sensitive subjects. Sociological Review 36 (3): 552-563.

Braudy Harris, P. and Keady, J. (2008) Wisdom, resilience and successful ageing: changing public discourses on living. Dementia 7 (1): 5-8.

Brodaty, H., Green, A. and Koschera, A. (2003) Meta-analysis of psychosocial interventions for caregivers of people with dementia. Journal of the American Geriatric Society 51 (5): 657-664.

Brody, E., Kleban, M., Lawton, M. and Silverman, H. (1971) Excess disabilities of mentally impaired aged: impact of individualized treatment. The Gerontologist 11 (2): 124-133.

Brooker, D. (2004) What is person-centred care in dementia? Reviews in Clinical Gerontology 13 (3): 215-222.

Brooker, D. (2007) Person-centred Dementia Care. Making Services Better. London: Jessica Kingsley Publishers.

Brouwer, W., van Exel, N.J., van den Berg, B., van den Bos, G. and Koopmanschap, M. (2005) Process utility from providing informal care: the benefit of caring. Health Policy 74 (1): 85-89.

Brown, J. and Chen, S.L. (2008) Help-seeking patterns of older spousal caregivers of older adults with dementia. Issues in Mental Health Nursing 29 (8): 839-852.

Brunton, K. (1997) Stigma. Journal of Advanced Nursing 26 (5): 891-898.

Bryant, A. and Charmaz, K. (2007) The Sage Handbook of Grounded Theory. Los Angeles: Sage Publications.

Buckley, C. and McCarthy, G. (2009) An exploration of social connectedness as perceived by older adults in a long-term care setting in Ireland. Geriatric Nursing 30 (6): 390-396.

Burgess, R.G. (1984) In the Field: An Introduction to Field Research. London: Unwin Hyman.

Burke Draucker, C., Martsolf, D. and Poole, C. (2009) Developing distress protocols for research on sensitive topics. Archives of Psychiatric Nursing 23 (5): 343-350.

Burkitt, I. (1999) Between the dark and the light: power and the material contexts of social relations In: Nightingale, D. and Cromby, J. (eds) Social Constructionist Psychology. Buckingham: Open University Press.

Burkitt, I. (2008) Social Selves. Theories of Self and Society. 2nd Edition. London: Sage.
Burningham, K. and Cooper, G. (1999) Being constructive: social constructionism and the environment. Sociology 33 (2): 297-316.

Burr, V. (2003) Social Constructionism. 2nd Edition. Hove, East Sussex: Routledge.

Butcher, H.K., Holkup, P. and Buckwalter, K.C. (2001) The experience of caring for a family member with Alzheimer's disease. Western Journal of Nursing Research 23 (1): 33-55.

Butler, C. (2002) Postmodernism. A Very Short Introduction. Oxford: Oxford University Press.

Byrne, P. (2000) Stigma of mental illness and ways of diminishing it. Advances in Psychiatric Treatment 6 (1): 65-72.

Byrne, P. (2001) Psychiatric stigma. British Journal of Psychiatry 178 (3): 281-284

Bytheway, B. and Johnson, J. (2008) The social construction of carers In: Johnson, J. and De Souza, C. (eds) Understanding Health and Social Care. An Introductory Reader. 2nd Edition. Milton Keynes: The Open University.

Cahill, S., Clark, M., Walsh, C., O'Connell, H. and Lawlor, B. (2006) Dementia in primary care: the first survey of Irish general practitioners. International Journal of Geriatric Psychiatry 21 (4): 319-324.

Cantley, C. and Bowes, A. (2004) Dementia and social inclusion: the way forward In: Innes, A., Archibold, C. and Murphy, C (ed) Dementia and Social Exclusion. London: Jessica Kingsley.

Care Alliance (2008) Health and Wellbeing in Carers in Ireland (online). Care Alliance. Available: http://www.carealliance.ie/documents/CAI_Presentation_28thOct2008[1].pdf (15th December 2008).

Caron, C. and Bowers, B. (2003) Deciding whether to continue, share, or relinquish caregiving: caregiver views. Qualitative Health Research 13 (9): 1252-1271.

Carpentier, N. and Ducharme, F. (2003) Care-giver network transformations: the need for an integrated perspective. Ageing and Society 23 (4): 507-525.

Carpentier, N. and Ducharme, F. (2005) Support network transformations in the first stages of the caregiver's career. Qualitative Health Research 15 (3): 289-311.

Carpentier, N., Ducharme, F., Kergoat, M.J. and Bergman, H. (2008) Social representations of barriers to care early in the careers of caregivers of persons with Alzheimer's disease. Research on Aging 30 (3): 334-357.

Carretero, S., Garces, J., Rodenas, F. and Sanjose, V. (2009) The informal caregiver's burden of dependent people: theory and empirical review. Archives of Gerontology and Geriatrics 49 (1): 74-79.

Carter, S. and Little, M. (2007) Justifying knowledge, justifying method, taking action: epistemologies, methodologies, and methods in qualitative research. Qualitative Health Research 17 (10): 1316-1328.

Cassell, E. (1976) Disease as an 'it': concepts of disease revealed by patient's presentation of symptoms. Social Science and Medicine 10 (3-4): 143-146.

Chambers, D. and Narayanasamy, A. (2008) A discourse and Foucauldian analysis of nurses health beliefs: implications for nurse education. Nurse Education Today 28 (1): 155-162.

Champlin, B. (2009) Being there for another with a serious mental illness. Qualitative Health Research 19 (11): 1525-1535.

Chang, K.H. and Horrocks, S. (2006) Lived experiences of family caregivers of mentally ill relatives. Journal of Advanced Nursing 53 (4): 435-443.

Chappell, N. and Parmenter, G. (2005) The challenge of caregiving In: Minichiello, V. and Coulson, I. (eds) Contemporary Issues in Gerontology. Promoting Positive Ageing. Abingdon: Routledge.

Chappell, N. and Reid, R.C. (2002) Burden and well-being among caregivers: examining the distinction. The Gerontologist 42 (6): 772-780.

Charmaz, K. (1991) Good Days Bad Days. The Self in Chronic Illness and Time. New Brunswick: Rutgers University Press.

Charmaz, K. (1994) The grounded theory method: an explication In: Glaser, B. (ed) More Grounded Theory Methodology: a Reader. Mill Valley CA: Sociology Press.

Charmaz, K. (2003) 'Grounded theory, objectivist and constructivist methods' Strategies of Qualitative Inquiry. 2nd Edition. Thousand Oaks: Sage Publications.

Charmaz, K. (2005) Grounded theory in the 21st century. Applications for advancing social justice studies In: Denzin, N. and Lincoln, Y. (eds) The Sage Handbook of Qualitative Research. 3rd Edition. Thousand Oaks: Sage Publications.

Charmaz, K. (2006) Constructing Grounded Theory. London: Sage Publications.

Chen, H.Y. and Boore, J. (2009) Using a synthesised technique for grounded theory in nursing research. Journal of Clinical Nursing 18 (16): 2251-2260.

Cheston, R. and Bender, M. (2003) Understanding Dementia: the Man with the Worried Eyes. London: Jessica Kingsley Publishers.

Ching-Ching Chung, J. (1997) Focus on family care givers for individuals with dementia: implications for occupational therapy practice. Occupational Therapy International 4 (1): 66-80.

Chiovitti, R. and Piran, N. (2003) Rigour and grounded theory. Journal of Advanced Nursing 44 (4): 427-435.

Christiansen, O. (2007) A simpler understanding of classic grounded theory In: Glaser, B. and Holton, J. (eds) The Grounded Theory Seminar Reader. Mill Valley, CA: Sociology Press.

Christie, J. and Cunningham, C. (2009) Caring for People with Dementia in Acute Care Settings. Stirling: The Dementia Services Development Centre, University of Stirling.

Clare, L. (2002) Developing awareness about awareness in early stage dementia: the role of psychosocial factors. Dementia 1 (3): 295-312.

Clark, A. (1998) The qualitative-quantitative debate: moving from positivism and confrontation to post-positivism and reconciliation. Journal of Advanced Nursing 27 (6): 1242-1249.

Clarke, A. (2005) Situational Analysis Grounded Theory After the Postmodern Turn. Thousand Oaks, California: Sage.

Clarke, A. (2006) Qualitative interviewing: encountering ethical issues and challenges. Nurse Researcher 13 (4): 19-28.

Clarke, C. (1999) Dementia care partnerships: knowledge, ownership and exchange In: Adams, T. and Clarke, C. (eds) Dementia Care. Developing Partnerships in Practice. London: Bailliere Tindall.

Colello, K. (2007) Family Caregiving to the Older Population: Background, Federal Programs and Issues for Congress (online). Congressional Research Service, Domestic Social Policy Division. Available: http://digitalcommons.ilr.cornell.edu/key-workplace/322. (9th April 2009).

Collins, C. and Jones, R. (1997) Emotional distress and morbidity in dementia carers: a matched comparison of husbands and wives. International Journal of Geriatric Psychiatry 12 (12): 1168-1173.

Connell, C.M., Janevic, M.R. and Gallant, M.P. (2001) The costs of caring: impact of dementia on family caregivers. Journal of Geriatric Psychiatry and Neurology 14 (4): 179-187.

Cooke, D.D., McNally, L., Mulligan, K.T., Harrison, M.J.G. and Newman, S. (2001) Psychosocial interventions for caregivers of people with dementia: a systematic review. Aging and Mental Health 5 (2): 120-135.

Cooper, C., Balamurali, T., Selwood, A. and Livingston, G. (2007) A systematic review of intervention studies about anxiety in caregivers of people with dementia. International Journal of Geriatric Psychiatry 22 (3): 181-188.

Corbin, J. and Morse, J. (2003) The unstructured interactive interview: issues of reciprocity and risks when dealing with sensitive topics. Qualitative Inquiry 9 (3): 335-354.

Corbin, J. and Strauss, A. (2008) Basics of Qualitative Research. 3rd Edition. Los Angeles: Sage Publications.

Corner, L. and Bond, J. (2004) Being at risk of dementia: fears and anxieties of older adults. Journal of Aging Studies 18 (2): 143-155.

Corner, L., Brittain, K. and Bond, J. (2007) Social aspects of ageing. Psychiatry 6 (12): 480-483.

Corrigan, P.W., Watson, A.C., Byrne, P. and Davis, K. (2005) Mental health illness stigma: problem of public health or social justice? Social Work 50 (4): 363-368.

Council for International Organisation of Medical Sciences (CIOMS) (2002) Ethical Guidelines for Biomedical Research Involving Human Subjects. Guideline 13. Geneva Switzerland: Council for International Organisation of Medical Sciences

Creswell, J., Hanson, W., Clark Plano, V. and Morales, A. (2007) Qualitative research designs: selection and implementation. The Counselling Psychologist 35 (2): 236-264.

Crocker, J., Major, B. and Steele, C. (1998) 'Social Stigma' Boston: McGraw Hill.

Crooks, V. (2007) Exploring the altered daily geographies and lifeworlds of women living with fibromyalgia syndrome: A mixed-method approach. Social Science and Medicine 64 (3): 577-588.

Crotty, M. (1998) The Foundations of Social Resarch. Meaning and Perspective in the Research Process. London: Sage Publications.

Croucher, S. (2004) Globalization and Belonging. The Politics of Identity in a Changing World. Lanham: Rowman and Littlefield Publishers Inc.

Cutcliffe, J. (2005) Adapt or adopt: developing and transgressing the methodological boundaries of grounded theory. Journal of Advanced Nursing 51 (4): 421-428.

Cutcliffe, J. and Harder, H. (2009) The perpeptual search for parsimony: enhancing the epistemological and practical utility of qualitative research findings. International Journal of Nursing Studies 46 (10): 1401-1410.

Dalley, G. (1996) Ideologies of Caring: Rethinking Community and Collectivisim. 2nd Edition. London: MacMillan Press.

Daly, K. (1997) Re-placing theory in ethnography: a postmodern view. Qualitative Inquiry 3 (3): 343-365.

Davies, B. and Harre, R. (1990) Positioning: the discursive production. Journal for the Theory of Social Behaviour 20 (1): 43-64.

Davies, S. and Nolan, M. (2008) Attending to relationships in dementia care In: Downs, M. and Bowers, B. (eds) Excellence in Dementia Care. Research into Practice. Maidenhead: McGraw-Hill/Oxford University Press.

Davis, D. (2004) Dementia: sociological and philosophical constructions. Social Science and Medicine 58 (2): 369-278.

Degnen, C. (2007) Minding the gap: the construction of old age and oldness among peers. Journal of Aging Studies 21 (1): 69-80.

Delaney, S., Keegan, O. and McGee, H. (2002) Public and Patient Participation in Healthcare. A Discussion Paper for the Irish Health Service. Dublin: The Office for Health Management.

Denzin, N. (2007) Grounded theory and the politics of interpretation In: Bryant, A. and Charmaz, K. (eds) The Sage Handbook of Grounded Theory. Los Angeles: Sage Publications.

Denzin, N. and Lincoln, Y. (2005) The Sage Handbook of Qualitative Research. Thousand Oaks: Sage Publications.

Department of Health (2008) Carers at the Heart of 21st Century Families and Communities. London: Department of Health.

Department of Health (2009) Living Well with Dementia. A National Dementia Strategy. London: Department of Health.

Department of Health and Children (2006) A Vision for Change: Report on the Expert Group on Mental Health Policy. Dublin: The Stationery Office.

Department of Health and Children (2008) Home Care Support Package (online). Department of Health and Children. Available: http://www.dohc.ie/public/information/health_services_for_ older_people /home_ care_support_s cheme_for_carers.html (15th July 2009).

Department of the Taoiseach (2006) Towards 2016. Ten-Year Framework Social Partnership Agreement 2006-2015. Dublin: The Stationery Office.

Dewey, J. (1954) The Public and Its Problems. Chicago: The Swallow Press.

Dewing, J. (2008) Personhood and dementia: revisiting Tom Kitwood's ideas. International Journal of Older People Nursing 3 (1): 3-13.

Dey, I. (1999) Grounding Grounded Theory. San Diego: Academic Press.

Dey, I. (2004) Grounded theory In: Seale, C., Gobo, G., Gubrium, J. and Silverman, D. (eds) Qualitative Research Practice. London: Sage Publications.

Diaz Moore, K. (2004) Interpreting the "hidden program" of a place: an example from dementia day care. Journal of Aging Studies 18 (3): 297-320.

DiCicco-Bloom, B. and Crabtree, B. (2006) The qualitative research interview. Medical Education 40 (4): 314-321.

Dickens, P. (1996) Reconstructing Nature: Alienation, Emancipation and the Division of Labour. London: Routledge.

Dilworth-Anderson, P. (2001) Family issues and the care of persons with Alzheimer's disease. Aging and Mental Health 5 (Supplement 1): S49-S51.

Doherty, D., Benbow, S.M., Craig, J. and Smith, C. (2009) Patients' and carers' journeys through older people's mental health services. Dementia 8 (4): 501-513.

Doka, K. (2004) Living with Grief Alzheimer's Disease. Washington: Hospice Foundation of America.

Downs, M. (2000) Dementia in a socio-cultural context: an idea whose time has come. Ageing and Society 20 (3): 369-375.

Downs, M., Clare, L. and Mackenzie, J. (2006) Understandings of dementia: explanatory models and their implications for the person with dementia and therapeutic effort In: Hughes, J., Louw, S. and Sabat, S. (eds) Dementia. Mind, Meaning and the Person. Oxford: Oxford University Press.

Duffy, F.J.R. (2009) Involving relatives and carers In: Kydd, A., Duffy, T. and Duffy, F.J.R. (eds) The Care and Wellbeing of Older People. Exeter: Reflect Press.

Duggan, S., Blackman, T., Martyr, A. and Van Schaik, P. (2008) The impact of early dementia on outdoor life: A 'shrinking world'? Dementia 7 (2): 191-204.

Duggleby, W., Williams, A., Wright, K. and Bollinger, S. (2009) Renewing everyday hope: the hope experience of family caregivers of persons with dementia. Issues in Mental Health Nursing 30 (8): 514-521.

Dyck, I. (1995) Hidden geographies: the changing lifeworlds of women with multiple sclerosis. Social Science and Medicine 40 (3): 307-320.

Edley, N. (2001) Unravelling social constructionism. Theory and Psychology 11 (3): 433-441.

Edwards, A.B., Zarit, S.H., Stephens, M. and Townsend, A. (2002) Employed family caregivers of cognitively impaired elderly: an examination of role strain and depressive symptoms. Aging and Mental Health 6 (1): 55-61.

Edwards, C. and Imrie, R. (2003) Disability and bodies as bearers of value. Sociology 37 (2): 239-256.

Eide, P. and Kahn, D. (2008) Ethical issues in the qualitative researcher participant relationship. Nursing Ethics. 15 (2): 199-207.

Elliott, N. and Lazenbatt, A. (2005) How to recognise a quality grounded theory research study. Australian Journal of Advanced Nursing 22 (3): 48-52.

Emden, C. and Sandelowski, M. (1998) The good, the bad and the relative, part one: conceptions of goodness in qualitative research. International Journal of Nursing Practice 4 (4): 206-212.

Estes, C.L. and Binney, E. (1989) The biomedicalisation of aging: dangers and dilemmas. The Gerontologist 29 (5): 587-596.

Farran, C. (1997) Theoretical perspective concerning positive aspects of caring for elderly persons with dementia: stress/adaptation an existentialism. The Gerontologist 37 (2): 250-256.

Farran, C., Keane-Hagerty, E., Salloway, S., Kupferer, S. and Wilken, C. (1991) Finding meaning: an alternative paradigm for Alzheimer's disease family caregivers. The Gerontologist 31 (4): 483-489.

Farran, C., Loukissa, D., Perraud, S. and Paun, O. (2004) Alzheimer's disease caregiving information and skills. Part II: family caregiver issues and concerns. Research in Nursing and Health 27 (1): 40-51.

Farran, C., Miller, B., Kaufman, J., Donner, E. and Fogg, L. (1999) Finding meaning through caregiving: development of an instrument for family caregivers of persons with Alzheimer's disease. Journal of Clinical Psychology 55 (9): 1107-1125.

Fast, T., Williamson, D. and Keating, N. (1999) The hidden costs of informal elder care. Journal of Family and Economic Issues 20 (3): 302-326.

Faubian, J. (2002) The Essential Works of Michel Foucault 1954-1984. Volume 3: Power. London: Penguin Books.

Feld, S. and Basso, K. (1996) Senses of Place. Santa Fe: School of American Research Press.

Ferris, S. and Kluger, A. (1996) Commentary on age-associated memory impairment, age-related cognitive decline and mild cognitive impairment. Aging Neuropsychology Cognition 3 (2): 148-153.

Ferri, C., Prince, M., Brayne, C., Broadty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P., Rimmer, E., Scazufca, M. and Alzheimer's Disease International. (2005) Global prevalence of dementia: a Delphi study. Lancet 17 (366): 2112-2117.

Fine, M. (2007) Expanding the methodological imagination. The Counselling Psychologist 35 (3): 459-473.

Finlay, L. (2002) "Outing" the researcher: the provenance, process and practice of reflexivity. Qualitative Health Research 12 (4): 531-545.

Flaming, D. (2006) The ethics of Foucault and Ricouer: an underrepresented discusssion in nursing. Nursing Inquiry 13 (3): 220-227.

Flick, V., Von Kardorff, E. and Steinke, I. (2004) A Companion to Qualitative Research. London: Sage Publications.

Forbat, L. (2008) Social policy and relationship-centred dementia nursing In: Adams, T. (ed) Dementia Care Nursing. Promoting Well-being in People with Dementia and their Families. Basingstoke: Palgrave Macmillan.

Fortinsky, R.H. (2001) Health care triads and dementia care: integrative framework and future directions. Aging and Mental Health 5 (Supplement 1): S35-S48.

Foucault, M. (1972) The Archaelogy of Knowledge. London: Tavistock.

Foucault, M. (1973) The Birth of the Clinic: An Archaeology of Medical Perception. London: Tavistock.

Foucault, M. (1976) The History of Sexuality: An Introduction. Harmondsworth: Penguin.

Foucault, M. (1979) Discipline and Punish. Harmondsworth: Penguin.

Foucault, M. (1980) Power/Knowledge. New York: Pantheon.

Foucault, M. (1985) The Use of Pleasure. The History of Sexuality: 2. London: Penguin Books.

Foucault, M. (1990) The Care of the Self. The History of Sexuality 3. London: Penguin.

Foucault, M. (2002) The birth of social medicine In: Faubian, J. (ed) Power, Essential Works of Foucault 1954-1984. Volume three. London: Penguin Books.

Freshwater, D. (2000) Transformatory Learning in Nurse Education. Southsea Hants: Nursing Praxis International.

Freshwater, D. (2005) Writing, rigour and reflexivity in nursing research. Journal of Research in Nursing 10 (3): 311-315.

Fudge, H., Neufeld, A. and Harrison, M.J. (1997) Social networks of women caregivers. Public Health Nursing 14 (1): 20-27.

Funk, L.M. and Stajduhar, K. (2009) Interviewing family caregivers: implications of the caregiving context for the research interview. Qualitative Health Research 19 (6): 859-867.

Gaines, A. and Whitehouse, P. (2006) Building a mystery. Alzheimer's disease, mild cognitive impairment, and beyond. Philosophy, Psychiatry and Psychology 13 (1): 79-82.

Gallicchio, L., Siddiqi, N., Langenberg, P. and Baumgarden, M. (2002) Gender differences in burden and depression among informal caregivers of demented elders in the community. Journal of Geriatric Psychiatry 17 (2): 154-163.

Galvin, K., Todres, L. and Richardson, M. (2005) The intimate mediator: a carer's experience of Alzheimer's. Scandinavian Journal of Caring Sciences 19 (1): 2-11.

Garey, A., Hansen, R., Hertz, R. and MacDonald, C. (2002) Care and kinship: an introduction. Journal of Family Issues 23 (6): 703-715.

Garity, J. (1997) Stress, learning style, resilience factors, and ways of coping in Alzheimer family caregivers. American Journal of Alzheimer's Disease and Other Dementias 12 (4): 171-178.

Garner, J. (1997) Dementia: an intimate death. British Journal of Medical Psychology 70 (2): 177-184.

Gates, K. (2000) The experience of caring for a loved one. A phenomenological study. Nursing Science Quarterly 13 (1): 54-59.

Gaugler, J., Davey, A., Pearlin, L. and Zarit, S. (2000) Modeling caregiver adaptation over time: the longitudinal impact of behaviour problems. Psychology and Ageing 15 (3): 437-450.

Geertz, C. (1973) The Interpretation of Cultures. New Yok: Basic Books.

George, L. (2005) Stress and coping In: Johnson, M. (ed) The Cambridge Handbook of Age and Ageing. Cambridge: Cambridge University Press.

Georges, J., Jansen, S., Jackson, J., Meyrieux, A., Sadowska, A. and Slemes, M. (2008) Alzheimer's disease in real life - the dementia carer's survey. International Journal of Geriatric Psychiatry 23 (5): 546-551.

Gergen, K. (1999) An Invitation To Social Construction. London: Sage Publications.

Gergen, K. (2001) Construction in constructionism: toward consequential resolutions. Theory and Psychology 11 (3): 419-432.

Gergen, K. (2009) An Invitiation to Social Construction. 2nd Edition. Los Angeles: Sage Publications.

Gershenson Hodgson, L. and Cutler, S. (1997) Anticipatory dementia and well-being. The American Journal of Alzheimer's Disease 12 (2): 62-66.

Gillett, G. (2004) Clinical medicine and the quest for certainty. Social Science and Medicine 58 (4): 727-738.

Gilmour, L. (ed) (2003) Collins Concise Dictionary and Thesaurus. 3rd Edition. Glasgow: Harper Collins Publishers.

Given, B. and Given, C. (1991) Family caregiving for the elderly. Annual Review of Nursing Research 9: 77-101.

Given, C., Given, B., Stommel, V. and Azzouz, F. (1999) The impact of new demands for assistance on caregiver depression: tests using an inception cohort. The Gerontologist 39 (1): 76-85.

Glaser, B. (1978) Theoretical Sensitivity. Mill Valley, CA: Sociology Press.

Glaser, B. (1992) Basics of Grounded Theory Analysis. Mill Valley, CA: Sociology Press.

Glaser, B. (1998) Doing Grounded Theory: Issues and Discussions. Mill Valley, CA: Sociology Press.

Glaser, B. (1999) The future of grounded theory. Qualitative Health Research 9 (6): 836-845.

Glaser, B. (2001) The Grounded Theory Perspective: Conceptualisation Contrasted with Description. Mill Valley, CA: Sociology Press.

Glaser, B. (2003) The Grounded Theory Perspective II: Description's Remodelling of Grounded Theory Methodology. Mill Valley, CA: Sociology Press.

Glaser, B. (2005) The Grounded Theory Perspective III: Theoretical Coding. Mill Valley, CA: Sociology Press.

Glaser, B. (2007) Doing formal theory In: Bryant, A. and Charmaz, K. (eds) The Sage Handbook of Grounded Theory. Los Angeles: Sage Publications.

Glaser, B. and Strauss, A. (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine de Gruyter.

Goffman, E. (1959) The Presentation of Self in Everyday Life. New York: Doubleday Anchor.

Goffman, E. (1963) Stigma: notes on the management of spoiled identity. Englewood Cliffs, New Jersey: Prentice-Hall.

Goffman, E. (1974) Frame Analysis: An Essay on the Organization of Experience. Cambridge: Harvard University Press.

Goldsmith, M. (1986) Hearing the Voices of People with Dementia. Opportunities and Obstacles. London: Jessica Kingsley.

Goldsteen, M., Abma, T., Oeseburg, B., Verkerk, M., Verhey, F. and Widdershoven, G. (2007) What is it like to be a daughter? Identities under pressure in dementia care. Bioethics 21 (1): 1-12.

Gottlieb, B. and Wolfe, J. (2002) Coping with family caregiving to persons with dementia: a critical review. Aging and Mental Health 6 (4): 325-342.

Government of Ireland (2001) Primary Care a New Direction. Dublin: The Stationery Office.

Government of Ireland (2003) The Data Protection Act. Dublin: The Stationery Office.

Government of Ireland (2007a) National Action Plan for Social Inclusion 2007-2016. Dublin: The Stationery Office.

Government of Ireland (2007b) A Social Portrait of Older People in Ireland. Dublin: The Stationery Office.

Grafstrom, M., Fratiglioni, L. and Winbald, B. (1994) Caring for an elderly person: predictors of burden in dementia care. International Journal of Geriatric Psychiatry 9 (5): 373-379.

Graham, N., Lindesay, J., Katona, C., Bertolote, J.M., Camus, V., Copeland, J., de, M., Lima, C.A., Gaillard, M., Gely, N., M.C., Gray, J., Jacobsson, L., Kingma, M., Huhne, N., O'Loughlin, A., Rutz, W., Saraceno, B., Taintor, Z. and Wancata, J. (2003) Reducing stigma and discrimination against older people with mental disorders: a technical consensus statement. International Journal of Geriatric Psychiatry 18 (8): 670-678.

Grant, G. and Nolan, M. (1993) Informal carers: sources and concomitants of satisfaction. Health and Social Care in the Community 1 (3): 147-159.

Green, S., Davis, C., Karshmer, E., Marsh, P. and Straight, B. (2005) Living stigma: the impact of labeling, stereotyping, separation, status loss and discrimination in the lives of individuals with disabilities and their families. Sociological Inquiry. 75 (2): 197-215.

Grytten, N. and Maseide, P. (2005) 'What is expressed is not always what is felt': coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. Chronic Illness 1 (31): 231-243.

Guba, E. and Lincoln, Y. (1994) Competing paradigms in qualitative research In: Denzin, N. and Lincoln, Y. (eds) Handbook of Qualitative Research. Thousand Oaks: Sage.

Gubrium, J. (1986) Oldtimers and Alzheimer's: the descriptive organization of senility. Grenwich, CT: Jai Press.

Gubrium, J. (1987) Structuring and destructuring the course of illness: the Alzheimer's disease experience. Sociology of Health and Illness 9 (1): 1-24.

Gubrium, J. (1995) Taking stock. Qualitative Health Research 5 (3): 267-269.

Gubrium, J. and Holstein, J. (eds) (2008) Handbook of Constructionist Research. New York: Guildford.

Haase, T. (2005) Early Onset Dementia: A Needs Analysis of Younger People with Dementia in Ireland. Dublin: The Alzheimer Society of Ireland.

Hackely, C. (1998) Social Constructionism and research in marketing and advertising. Qualitative Market Research: An International Journal 1 (3): 125-131.

Hagerty, B., Lynch-Sauer, J., Patusky, K., Bouwsema, M. and Collier, P. (1992) Sense of belonging: a vital mental health concept. Archives of Psychiatric Nursing 6 (3): 172-177.

Hagerty, B. and Williams, R. (1999) The effects of sense of belonging, social support, conflict and loneliness on depression. Nursing Research 48 (4): 215-219.

Halding, A.G., Wahl, A. and Heggdal, K. (2010) 'Belonging'. 'Patients' experiences of social relationships during pulmonary rehabilitation. Disability and Rehabilitation. (online) Available: http://informahealthcare.com/doi/pdf/10.3109/09638280903464471 (22nd February 2010)

Hall, W. and Callery, P. (2001) Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. Qualitative Health Research 11 (2): 257-272.

Hammersley, M. (1992) What's Wrong With Ethnography?: Methodological Explorations London: Routledge.

Hammersley, M. and Atkinson, P. (1995) Ethnography. Principles in Practice. 2nd Edition. London: Routledge.

Hand, H. (2003) The mentor's tale: a reflexive account of semi-structured interviews. Nurse Researcher 10 (3): 15-27.

Hardin, P. (2001) Theory and language: locating agency between free will and discursive marionettes. Nursing Inquiry 8 (1): 11-18.

Harding, N. and Palfrey, C. (1997) The Social Construction of Dementia. Confused Professionals? London: Jessica Kingsley Publishers.

Harlton, S.V., Fast, J. and Keating, N. (1998) Defining eldercare for policy and practice: perspectives matter. Family Relations 47 (3): 281-288.

Harwood, D., Barker, W., Ownby, R., Bravo, M., Aguero, H. and Duara, R. (2000) Predictors of positive and negative appraisal among Cuban American caregivers of Alzheimer's disease patients. International Journal of Geriatric Psychiatry 15 (6): 481-487.

Haun, J., Rittman, M. and Sberna, M. (2008) The continuum of connectedness and social isolation during post stroke recovery. Journal of Aging Studies 22 (1): 54-64.

Haverkamp, B. and Young, R. (2007) Paradigms, purpose, and the role of the literature: formulating a rationale for qualitative investigations. The Counselling Psychologist 35 (2): 265-294.

Hayes, J., Boylestein, C. and Zimmerman, M. (2009) Living and loving with dementia: negotiating spousal and caregiver identitiy through narrative. Journal of Aging Studies 23 (1): 48-59.

Health Services Executive (2006) Transformation Programme 2007-2010. Dublin: Health Services Executive.

Health Services Executive (2008) The Journey Together. Information Booklet for Families and Friends who Support People Experiencing Mental Health Problems. Dublin: Health Services Executive.

Heath, H. and Cowley, S. (2004) Developing a grounded theory approach: comparison of Glaser and Strauss. International Journal of Nursing Studies 41 (1): 141-150.

Heaton, J. (1999) The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. Sociology of Health and Illness 21 (6): 759-777.

Hellstrom, I., Nolan, M. and Lundh, U. (2005) Awareness context theory and the dynamics of dementia. Dementia 4 (2): 269-296.

Hellstrom, I., Nolan, M. and Lundh, U. (2007) Sustaining couplehood. Dementia 6 (3): 383-409.

Helmes, E., Green, B. and Almeida, O. (2005) Individual differences in the experience of burden in caring for relatives with dementia: role of personality and mastery. Australian Journal on Ageing 24 (4): 202-206.

Henwood, K. and Pidgeon, N. (1993) Qualitative research and psycological theorising In: Hammersly, M. (ed) Social Research Philosophy, Politics and Practice. London: Sage Publications.

Henwood, M. (1992) Through a Looking Glass Darkly: Community Care and Elderly People. London: King's Fund Institute.

Henz, U. (2009) Couples' provision of informal care for parents and parents-in-law: far from sharing equally? Ageing and Society 29 (3): 369-395.

Herd, P. and Harrington Meyer, M. (2002) Care work: invisible civic engagement. Gender Society 16 (5): 665-688.

Hess, J. (2003) Gadow's relational narrative: an elaboration. Nursing Philosophy 4 (2): 137-148.

Hewitt, J. (2007) Ethical components of researcher researched relationships in qualitative interviewing. Qualitative Health Research 17 (8): 1149-1159.

Hill, T.M. (2001) Western medicine and dementia: a deconstruction In: Adams, T. and Clarke, C. (eds) Dementia Care. Developing Partnerships in Practice. London: Bailliere Tindall.

Hodson, R. and Keady, J. (2008) Mild cognitive impairment: a review and nursing implications. British Journal of Nursing 17 (6): 368-373.

Holloway, I. and Wheeler, S. (2002) Qualitative Research in Nursing. 2nd Edition. Oxford: Blackwell Publishers.

Holstein, J. and Gubrium, J. (2007) Constructionist perspectives on the life course. Sociology Compass 1 (1): 335-352.

Holstein, M. (1997) Alzheimer's disease and senile dementia, 1885-1920: an interpretive history of disease negotiation. Journal of Aging Studies 11 (1): 1-13.

Holton, J. (2007) The coding process and its challenges In: Bryant, A. and Charmaz, K. (eds) The Sage Handbook of Grounded Theory. Los Angeles: Sage Publications.

Hooyman, N. and Kiyak, H.A. (2008) Opportunities and challenges of informal caregiving In: Social Gerontology. 8th Edition. Boston: Pearson Education Inc.

Horsburgh, D. (2003) Evaluation of qualitative research. Journal of Clinical Nursing 12 (2): 307-312.

Huckle, P. (1994) Families and dementia. International Journal of Geriatric Psychiatry 9 (9): 735-741.

Hughes, J., Louw, S. and Sabat, S. (eds) (2006a) Dementia, Mind, Meaning and the Person Oxford: Oxford University Press.

Hughes, J., Louw, S. and Sabat, S. (2006b) Seeing whole In: Hughes, J., Louw, S. and Sabat, S. (eds) Dementia, Mind, Meaning and the Person. Oxford: Oxford University Press.

Hunt, C. (2003) Concepts in caregiver research. Journal of Nursing Scholarship 3 (1): 27-32.

Huppert, F. and Brayne, C. (1994) What is the relationship between dementia and normal aging? In: Hupppert, F., Brayne, C. and O'Connor, D. (eds) Dementia and Normal Aging. Cambridge: Cambridge University Press.

Hutchinson, H.A., Wilson, M.E. and Wilson, H.S. (1994) Benefits of participating in research interviews. Image: Journal of Nursing Scholarship 26 (2): 161-164.

Hyde, A., Lohan, M. and McDonnell, O. (2004) Sociology for Health Professionals in Ireland. Dublin: Institute of Public Administration.

Iliffe, S., De, L., J , Van Hout, H., Kenny, G., Lewis, A., Vernooij-Dassen, M. and The Diadem Group (2005) Understanding the obstacles to the recognition of and response to dementia in different European countries: a modified focus group approach using multinational, multidisciplinary expert groups. Aging and Mental Health 9 (1): 1-6.

Innes, A. (2002) The social and political context of formal dementia care provision. Ageing and Society 22 (4): 483-499.

Innes, A. (2009) Dementia Studies. A Social Science Perspective. London: Sage.

International Council of Nurses (2003) Ethical Guidelines for Nursing Research. Geneva: International Council of Nurses.

Jansson, W., Nordberg, G. and Grafstrom, M. (2001) Patterns of elderly spousal caregiving in dementia care: an observational study. Journal of Advanced Nursing 34 (6): 804-812.

Jeon, Y.H. (2004) The application of grounded theory and symbolic interactionism. Scandinavian Journal of Caring Sciences 18 (4): 249-256.

Joachim, G. and Acorn, S. (2000) Stigma of visible and invisible chronic conditions. Journal of Advanced Nursing 32 (1): 243-248.

Johnson, B. and Clarke, J. (2003) Collecting sensitive data: the impact on researchers. Qualitative Health Research 13 (3): 421-434.

Johnson, M. (2005) The social construction of old age as a problem In: Johnson, M. (ed) The Cambridge Handbook of Age and Ageing. Cambridge: Cambridge University Press.

Johnson, R. and Onwuegbuzie, A. (2004) Mixed methods research: a research paradigm whose time has come. Educational Resarch 33 (7): 14-26.

Jolley, D. and Benbow, S. (2000) Stigma and Alzheimer's disease: causes consequences and a constructive approach. Journal of Clinical Practice 54 (2): 117-119.

Jones, E.E., Farina, A., Hastorf, A.H., Markus, H., Miller, D.T. and Scott, R.A. (1984) Social Stigma: the Psychology of Marked Relationships. New York: W.H. Freeman and Company.

Jones, K. (2006) Informal care as relationship: the case of the mangificent seven. Journal of Psychiatric and Mental Health Nursing 13 (2): 214-220.

Jones, R., Chow, T. and Gatz, M. (2006) Asian Americans and alzheimer's disease: assimilation, culture and beliefs. Journal of Aging Studies 20 (1): 11-25.

Kaiser, K. (2009) Protecting respondent confidentiality in qualitative research. Qualitative Health Research 19 (11): 1632-1641.

Karenberg, A. and Forstl, H. (2006) Dementia in the Greco-Roman world. Journal of Neurological Sciences 244 (1): 5-9.

Katsuno, T. (2005) Dementia from the inside - how people with early-stage dementia evaluate their quality of life. . Ageing and Society 25 (2): 197-214.

Keady, J. (1999) The dynamics of dementia: a modified grounded theory study. Bangor: University of Wales. PhD.

Keady, J., Ashcroft-Simpson, S., Halligan, K. and Williams, S. (2007) Admiral nursing and the family care of a parent with dementia: using autobiographical narrative as grounding for negotiated cinical practice and decision-making. Scandinavian Journal of Caring Sciences 21 (3): 345-353.

Keady, J. and Braudy Harris, P. (2009) Editorial: family matters. Dementia 8 (1): 5-8.

Keady, J. and Nolan, M. (2003) The dynamics of dementia: working together, working separately, or working alone? In: Nolan, M., Lundh, U., Grant, G. and Keady, J. (eds) Partnerships in family care:. Maidenhead: Open University Press.

Keating, N., Fast, T., Connidis, I., Penning, M. and Keefe, J. (1997) Bridging policy and research in eldercare. Special joint issue. Canadian Journal on Aging and Canadian Public Policy 23 (Supplement): 22-41.

Keats, D.M. (2000) Interviewing a practical guide for students and professionals. Buckingham: Open University Press.

Keddy, B., Sims, S. and Stern, P.N. (1996) Grounded theory and feminist research methodology. Journal of Advanced Nursing 23 (3): 448-453.

Kennedy, T. and Lingard, L. (2006) Making sense of grounded theory in medical education. Medical Education 40 (2): 101-108.

Keogh, B. and Daly, L. (2009) The ethics of conducting research with mental health service users. British Journal of Nursing 18 (5): 277-281.

Keogh, C. and McGettrick, G. (2008) Social Space: Equal Place. The Social Club Model of Dementia Care: A Research Report. Dublin: The Alzheimer Society of Ireland.

Kim, Y. and Schulz, R. (2008) Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes and frail elderly caregiving. Journal of Aging and Health 20 (5): 483-503.

Kirkwood, T. (2006) Alzheimer's disease, mild cognitive impairment and the biology of intrinsic aging. Philosophy, Psychiatry and Psychology 13 (1): 79-82.

Kitwood, T. (1990) The dialectics of dementia: with particular reference to Alzheimer's disease. Ageing and Society 10 (2): 177-198.

Kitwood, T. (1993a) Towards a theory of dementia care: the interpersonal process. Ageing and Society 13 (1): 51-67.

Kitwood, T. (1993b) Person and process in dementia. International Journal of Geriatric Psychiatry 8 (7): 541-545.

Kitwood, T. (1996) A dialectical framework for dementia. In: Woods, R.T. (ed) Handbook of the Clinical Psychology of Ageing. Chichester: Wiley.

Kitwood, T. (1997) Dementia Reconsidered: The Person Comes First. Buckingham: Open University Press.

Kitwood, T. and Benson, S. (1995) The New Culture of Dementia Care. London: Hawker Publications.

Kitwood, T. and Bredin, K. (1992) Towards a theory of dementia care: personhood and well-being. Ageing and Society 12 (3): 269-287.

Kleinman, A. (1988) The Illness Narratives. Suffering, Healing and the Human Condition. USA: Basic Books.

Knapik, M. (2006) The qualitative research interview: participants' responsive participation in knowledge making. International Journal of Qualitative Methods 5 (3). (Online) Available: http://www.ualberta.ca/~ijqm/ (1st July 2007).

Knight, B., Flynn Longmire, C., Dave, J., Kim, J.H. and David, S. (2007) Mental health and physical health of family caregivers for persons with dementia: a comparison of African American and white caregivers. Aging and Mental Health 11 (5): 538-546.

Koch, T. and Harrington, A. (1998) Reconceptualising rigour: the case for reflexivity. Journal of Advanced Nursing 28 (4): 882-890.

Koch, T. and Webb, C. (1996) The biomedical construction of ageing: implications for nursing care of older people. Journal of Advanced Nursing 23 (5): 954-959.

Kolanowski, A., Fick, D., Waller, J. and Shea, D. (2004) Spouses of persons with dementia: their healthcare problems, utilization, and costs. Research in Nursing and Health 27 (5): 296-306.

Kontos, P. and Naglie, G. (2007) Expressions of personhood in Alzheimer's disease: an evaluation of research-based theatre as a pedagogical tool. Qualitative Health Research 17 (6): 799-811.

Kramer, B. (1997) Gain in the caregiving experience: where are we? What next? The Gerontologist 37 (2): 218-232.

Krieger, S. (1991) Social Science and the Self: Personal essays on an art form. New Brunswick, NJ: Rutgers University Presss.

Krull, A. (2005) First signs and normalisations: caregiver routes to the diagnosis of Alzhemier's disease. Journal of Aging Studies 19 (4): 407-417.

Kruse, A. and Schmitt, E. (2006) A multidimensional scale for the measurement of agreement with age stereotypes and the salience of age in social interaction. Ageing and Society 26 (3): 393-411.

Kvale, S. (1996) Interviews: an Introduction to Qualitative Research Interviewing. Thousand Oaks: Sage Publications.

Kvale, S. (2006) Dominance through interviews and dialogue. Qualitative Inquiry 12 (3): 480-500.

Kvale, S. and Brinkman, S. (2009) Interviews. Learning the Craft of Qualitative Research Interviewing. Los Angeles: Sage.

Lalor, J., Begley, C. and Devane, D. (2006) Exploring painful experiences: impact of emotional narratives on members of a qualitative research team. Journal of Advanced Nursing 56 (6): 607-616.

Langdridge, D. (2004) Introduction to Research Methods and Data Analysis in Psychology. Harrow: Pearson Prentice Hall.

Lane, P., Mckenna, H., Ryan, A. and Fleming, P. (2000) Listening to the Voice of Carers. Ireland: South Eastern Health Board.

Laudan, L. (1977) Progress and its Problems. Towards a Theory of Scientific Growth. London: Routledge and Kegan Paul.

Lazarus, R.S. and Folkman, S. (1984) Stress, Appraisal and Coping. New York: Springer.

Leal Hill, D. (2009) Relationship between sense of belonging as connectedness and suicide in American Indians. Archives of Psychiatric Nursing 23 (1): 65-74.

Lee, R. and Renzetti, C. (1990) The problems of researching sensitive topics: an overview and introduction. American Behavioural Scientist 33 (5): 510-528.

Lee, R. and Robbins, S. (1995) Measuring belongingness: the social connectedness and the social assurance scales. Journal of Counseling Psychology 42 (2): 232-241.

Lee, R. and Robbins, S. (1998) The relationship between social connectedness and anxiety, self-esteem and social identity. Journal of Counseling Psychology 45 (3): 338-345.

Lempert, L.B. (2007) Asking questions of the data: memo writing in the grounded theory tradition In: Bryant, A. and Charmaz, K. (eds) The Sage Handbook of Grounded Theory. Los Angeles: Sage Publications.

Levett-Jones, T. and Lathlean, J. (2008) Belongingness: a pre-requisite for nursing students' clinical learning. Nurse Education in Practice 8 (2): 103-111.

Levy, T. (2006) The relational self and the right to give care. New Political Science 28 (4): 547-570.

Lewis, M., Hepburn, K., Narayan, S. and Nelson Kirk, L. (2005) Relationship matters in dementia caregiving. American Journal of Alzheimer's Disease and Other Dementias 20 (6): 341-347.

Lierbucks, A. (2001) The concept of social constructionism. Theory and Psychology 11 (3): 363-391.

Lincoln, Y. and Denzin, N. (2005) Epilogue. The eighth and ninth moments - qualitative research in/and the Fractured Future In: Denzin, N. and Lincoln, Y. (eds) The Sage Handbook of Qualitative Research. Thousand Oaks: Sage Publications.

Lincoln, Y. and Guba, E. (2003) Paradigmatic controversies, contradictions and emerging confluences In: Denzin, N. and Lincoln, Y. (eds) The Landscape of Qualitative Research Theories and Issues. 2nd Edition. Thousand Oaks: Sage Publications.

Lindgren, C. (1993) The caregiver career. Journal of Nursing Scholarship 25 (3): 214-219.

Link, B., Phelan, J., Bresnahan, M., Stueve, A. and Pscosolido, B. (1999) Public conceptions of mental illness: labels, causes, dangerousness and social distance. American Journal of Public Health 89 (9): 1328-1333.

Link, B. and Phelan, J.C. (2001) Conceptualising stigma. Annual Review of Sociology 27 (1): 262-285.

Lishman, W. (1994) The history of research into dementia and its relationship to current concepts In: Huppert, F., Brayne, C. and O'Connor, D. (eds) Dementia and Normal Aging. Cambridge: Cambridge University Press.

Lomborg, K. and Kirkevold, M. (2003) Truth and validity in grounded theory - a reconsidered realist interpretation of the criteria: fit, work, relevance and modifiability. Nursing Philosophy 4 (1): 189-200.

Long, T. and Johnson, M. (2000) Rigour, reliability and validity in qualitative research. Clinical Effectiveness in Nursing 4 (1): 30-37.

Lott, J. (2005) Vulnerable/special participant populations. Developing World Bioethics 5 (1): 30-54.

Lyman, K. (1989) Bringing the social back in: a critique of the biomedicalisation of dementia. The Gerontologist 29 (5): 597-605.

Lyotard, J.F. (1984) The Postmodern Condition: A Report on Knowledge. Mineapolis: University of Minnesota Press.

MacDonald, M. and Schreiber, R.S. (2001) Constructing and deconstructing: grounded theory in a postmodern world In: Schreiber, R.S. and Stern, P.N. (eds) Using Grounded Theory in Nursing. New York: Springer Publishing Company.

Macklin, R. (2003) Bioethics, vulnerability, and protection. Bioethics 17 (5,6): 472-486.

MacRae, H. (1999) Managing courtesy stigma: the case of Alzheimer's disease. Sociology of Health & Illness 21 (1): 54-70.

MacRae, H. (2008) 'Making the best you can of it': living with early-stage Alzheimer's disease. Sociology of Health and Illness 30 (3): 396-412.

Maijala, H., Paavilainen, E. and Astedt-Kurki, P. (2003) The use of grounded theory to study interaction. Nurse Researcher 11 (2): 40-58.

Mallory, C. (2001) Examining the difference between researcher and participant: an intrinsic element of grounded theory In: Schreiber, R.S. and Stern, P.N. (eds) Using Grounded Theory in Nursing. New York: Springer Publishing Company.

Mander, R. (1992) Seeking approval for research access: the gatekeeper's role in facilitating a study of the care of the relinquishing mother. Journal of Advanced Nursing 17 (12): 1460-1464.

Marshall, M. and Tibbs, M.A. (2006) Social Work and People with Dementia. Bristol: The Policy Press.

Martinez Lage, J.M. (2006) 100 Years of Alzheimer's disease. Journal of Alzheimer's Disease 9 (Supplement): 15-26.

Martorell Poveda, A. (2003) An anthropological perspective of Alzheimer Disease. Geriatric Nursing 24 (1): 26-31.

Maslow, A. (1954) Motivation and Personality. New York: Harper.

Marson, D. (2001) Loss of competency in Alzheimer's disease: conceptual and psychometric approaches. International Journal of Law and Psychiatry. 24 (2/3): 267-283.

Mavundla, T., Toth, F. and Mphelane, M. (2009) Caregiver experience in mental illness: a perspective from a rural community in South Africa. International Journal of Mental Health Nursing 18 (5): 357-367.

McCallin, A. (2003) Designing a grounded theory study: some practicalities. Nursing in Critical Care 8 (5): 203-208.

McCann, T. and Clark, E. (2005) Using unstructured interview with participants who have schizophrenia. Nurse Researcher 13 (1): 7-18.

McConaghy, R. and Caltabiano, M.L. (2005) Caring for a person with dementia: exploring relationships between perceived burden, depression, coping and well-being. Nursing and Health Sciences 7 (2): 81-91.

McCormack, B. (2004) Person-centredness in gerontological nursing: an overview. International Journal of Older People Nursing in association with the Journal of Clinical Nursing. 13 (3a): 31-38.

McDaid, D. (2001) Estimating the costs of informal care for people with Alzheimer's disease: methodological and practical challenges. International Journal of Geriatric Psychiatry 16 (4): 400-405.

McGarry, K. (2006) Does caregiving affect work? Evidence based on prior labor force experience In: Wise, D. and Yashiro, N. (eds) Health Care Issues in the US the Japan. Chicago: University of Chicago Press.

McGee, H., Molloy, G., O'Hanlon, A. and Hickey, A. (2008) Older people - recipients but also providers of informal care: an analysis among community samples in the Republic of Ireland and Northern Ireland. Health and Social Care in the Community 16 (5): 548-553.

McGhee, G., Marland, G.R. and Atkinson, J. (2007) Grounded theory research: literature review and reflexivity. Journal of Advanced Nursing 60 (3): 334-342.

McGlone, E. and Fitzgerald, F. (2005) Perceptions of Ageism in Health and Social Services in Ireland. Report no. 85. Dublin: National Council on Ageing and Older People.

McHugh, K. (2003) Three faces of ageism: society, image and place. Ageing and Society 23 (2): 165-185.

McKean Skaff, M., Pearlin, L. and Mullan, J. (1996) Transition in the caregiving career: effects on sense of mastery. Psychology and Ageing 11 (2): 247-257.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D. and Stadler, E. (1984) Clinical diagnosis of Alzheimer disease. Report of the NINCD-ADRDA working group, under the auspices of the Department of Health and Human Task Force on Alzheimer's Disease. Neurology 34 (7): 939-944.

Mead, D. (1993) Personal experiences of designing questionnaires. Nurse Researcher 1 (2): 62-70.

Melia, K. (1996) Rediscovering Glaser. Qualitative Health Research 6 (3): 368-378.

Mesenthos, E. and Triantafillou, J. (2005) EUROFAMCARE Group: Supporting Family Carers of Older People in Europe - the Pan-European Background. Hamburg: EUROFAMCARE-Consortium.

Miles, A. (1981) The Mentally Ill in Contemporary Society. Oxford: Martin Robertson.

Miller, L. (2008) Foucauldian constructionism In: Handbook of Constructionist Research. New York: The Guilford Press.

Miller, S. and Fredericks, M. (1999) How does grounded theory explain? Qualitative Health Research 9 (4): 538-551.

Milligan, C. (2003) Location or dis-location? Towards a conceptualisation of people and place in the care-giving experience? Social and Cultural Geography 4 (14): 455-470.

Mills, J., Bonner, A. and Francis, K. (2006a) Adopting a constructivist approach to grounded theory: implications for research design. International Journal of Nursing Practice 12 (1): 8-13.

Mills, J., Bonner, A. and Francis, K. (2006b) The development of constructivist grounded theory. International Journal of Qualitative Methods 5 (1): 1-10.

Mills, J., Chapman, Y., Bonner, A. and Francis, K. (2007) Grounded theory: a methodological spiral from positivism to postmodernism. Journal of Advanced Nursing 58 (1): 72-79.

Mills, P.J., Adler, K.A., Dimsdale, J., Perex, C.Z. and Ziegler, M.G. (2004) Vulnerable caregivers of Alzheimer's disease patients have a deficit in beta 2-adrenergic receptor sensitivity and density. American Journal of Geriatric Psychiatry 12 (3): 281-286.

Mills, S. (2004) Michel Foucault. Abingdon: Routledge.

Mishler, E. (1979) Meaning in context. Is there any other kind? Harvard Educational Review 49 (1): 1-19

Mishler, E. (1986) Research Interviewing: Context and Narrative. Cambridge, M.A: Harvard University Press.

Mishler, E. (1999) Storylines: Craftists' Narratives of Identity. Cambridge, MA: Harvard University Press.

Mittleman, M. (2003) Community caregiving. Alzheimer's Care Quarterly 4 (4): 273-285.

Montero-Rodriguez, J., Kosloski, K., Kercher, K. and Montogomery, R. (2009) The impact of social embarrassment on caregivng distress in a multicultural sample of caregivers. Journal of Applied Gerontology 28 (2): 195-217.

Montgomery, P. and Bailey, P. (2007) Field notes and theoretical memos in grounded theory. Western Journal of Nursing Research 29 (1): 65-79.

Montgomery, R. and Kosloski, K. (2009) Caregiving as a process of changing identity: implications for caregiver support. Generations - Journal of the American Society on Aging 33 (1): 47-52.

Montgomery, R.J.V. and Williams, K.N. (2001) Implications of differential impacts of care-giving for future research on Alzheimer care. Aging and Mental Health 5 (Supplement 1): S23-S34.

Moore, M., Zhu, C. and Clipp, E. (2001) Informal costs of dementia care: estimates from the National Longitudinal Caregiver Study. Journal of Gerontology 56B (4): S219-S228.

Mora-Rios, J., Medine-Mora, M., Ito Sugiyama, E. and Natera, G. (2008) The meanings of emotional ailments in a marginalised community in Mexico city. Qualitative Health Research 18 (6): 830-842.

Morgan, D., Semchuk, K., Stewart, N. and D'Arcy, C. (2002) Rural families caring for a relative with dementia: barriers to use of formal services. Social Science and Medicine 55 (7): 1129-1142.

Morris, G. and Morris. J. (2010) The Dementia Care Workbook. Maidenhead: Open University Press.

Morrow, S. (2007) Qualitative research in counselling psychology: conceptual foundations. The Counselling Psychologist 35 (2): 209-235.

Morse, J. (1994) Designing funded qualitative research In: Denzin, N. and Lincoln, Y. (eds) Handbook of Qualitative Research. London: Sage.

Morse, J. (2009) "Going beyond your data" and other dilemmas of interpretation. Qualitative Health Research 19 (5): 579.

Morton, L. (2003) Psychological journey of an Alzheimer's caregiver. Alzheimer's Care Quarterly 4 (4): 262-266.

Motenko, A.K. (1989) The frustrations, gratifications and well-being of dementia caregivers. The Gerontologist 29 (2): 166-172.

Munhall, P.L. (1991) Institutional review of qualitative research proposals: a task of no small importance In: Morse, J. (ed) Qualitative Nursing Research. Newbury Park California: Sage.

Murphy, E., Dingwall, R., Greatbatch, D., Parker, S. and Watson, P. (1998) Qualitative research methods in health technology assessment: a review of the literature. Health Technology Assessment 2 (16): 1-275.

National Alliance for Caregiving (2008) International Caregiving Legislation (online). Available: ://wwwcaregiving.org/intcaregiving/ireland/ireland.html (5th Sept 2009).

National Collaborating Centre for Mental Health (2007) The NICE-SCIE Guideline On Supporting People with Dementia and their Carers in Health and Social Care. National Clinical Practice Guideline Number 42. London: The British Psychological Society and The Royal College of Psychiatrists.

National Council on Ageing and Older People (2001) Carers Ageing in Ireland Fact File No. 9. Dublin: National Council on Ageing and Older People.

National Council on Ageing and Older People (2004) Population Aging in Ireland. Projections 2002-2021. Report No. 81. Dublin: National Council on Ageing and Older People.

National Disability Authority (2005) First Steps in Producing Accessible Publications. Dublin: National Disability Authority.

Naue, U. and Kroll, T. (2009) 'The demented other': identity and difference in dementia. Nursing Philosophy 10 (1): 26-33.

Neill, S. (2006) Grounded theory sampling: the contribution of reflexivity. Journal of Research in Nursing 11 (3): 253-260.

Neill, S. (2007) Grounded theory sampling: 'whole' family resaerch. Journal of Research in Nursing 12 (5): 435-443.

Netto, N.R., Goh, J. and Yap, P. (2009) Growing and gaining through caring for a loved one with dementia. Dementia 8 (2): 235-261.

Neufeld, A. and Harrison, M.J. (2003) Unfulfilled expectations and negative interactions: nonsupport in the relationships of women caregivers. Journal of Advanced Nursing 41 (4): 323-331.

Nicolson, M. and McLaughlin, C. (1987) Social constructionism and medical sociology: a reply. Sociology of Health and Illness 9 (2): 107-126.

Nightingale, D. and Cromby, J. (1999) Social Constructionist Psychology, a critical analysis of theory and practice. Buckingham: Open University Press.

Nightingale, D. and Cromby, J. (2002) Social constructionism as ontology: exposition and example. Theory and Psychology 12 (5): 701-713.

Nolan, L., McCarron, M., McCallion, P. and Murphy-Lawless, J. (2006) Perceptions of Stigma in Dementia: an Exploratory Study. (online) Dublin: Trinity College Dublin, School of Nursing and Midwifery. Available: http://www.alzheimer.ie/eng/Resources/Research/Perceptions-of-Stigma-in-Dementia-An-Exploratory-Study (13th April 2008).

Nolan, M., Davies, S., Brown, J., Keady, J. and Nolan, J. (2004) Beyond 'person-centred' care: a new vision for gerontological nursing. International Journal of Older People Nursing in association with Journal of Clinical Nursing. 13 (3a): 45-53.

Nolan, M., Grant, G. and Keady, J. (1996) Understanding Family Care: a multidimensional model of caring and coping. Buckingham: Open University Press.

Nolan, M., Lundh, U., Grant, G. and Keady, J. (2003) Partnerships in Family Care: understanding the caregiving career. Maidenhead: Open University Press.

Nolan, M., Ryan, T., Enderby, P. and Reid, D. (2002) Towards a more inclusive vision of dementia care practice and research. Dementia: The International Journal of Social Research and Practice 1 (2): 193-211.

Norton, L. (1999) The philosophical bases of grounded theory and their implications for research. Nurse Researcher 7 (1): 31-43.

Nuffield Council on Bioethics (2009) Dementia: Ethical Issues. Cambridge: Cambridge Publishers Limited.

Nunkoosing, K. (2005) The problems with interviews. Qualitative Health Research 15 (5): 698-706.

O'Brien, S. (2003) Writing Effective Health Information Materials. Guidelines on writing and design technique. Dublin: Health Promotion Unit and National Adult Literacy Agency.

O'Callaghan, S. (2008) Irish Statistics (online). Alzheimer Society of Ireland. Available: http://www.alzheimer.ie/eng/layout/set/print/Media-Centre/Facts-About-Dementia/Irish-Statistics (10th February 2009).

O'Connor, D. (2007) Self-identifying as a caregiver: exploring the positioning process. Journal of Aging Studies 21 (2): 165.

O'Connor, D., Phinney, A. and Hulko, W. (2009) Dementia at the intersections: a unique case study exploring social location. Journal of Aging Studies 24 (1): 30-39.

O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., Drance, E., Donnelly, M., Chaudhury, H. and Beattie, L. (2007) Personhood in dementia care. Developing a research agenda for broadening the vision. Dementia 6 (1): 121-142.

O'Connor, J. and Ruddle, H. (1988) Caring for the Elderly Part II. The Caring Process: A Study of Carers in the Home. Report No. 19. Dublin: National Council for the Aged.

O'Shea, E. (2003) Costs and consequences for the carers of people with dementia in Ireland. Dementia 2 (2): 201-219.

O'Shea, E. (2007) Implementing Policy for Dementia Care in Ireland. Galway: Irish Centre for Socal Gerontology, National University of Ireland.

O'Shea, E. and O'Reilly, S. (1999) An Action Plan for Dementia. Dublin: National Council on Ageing and Older People.

Okabayashi, H., Sugisawa, H., Takanashi, K., Nakatani, Y., Sugihara, Y. and Hougham, G. (2008) A longitudinal study of coping and burnout among Japanese family caregivers of frail elders. Ageing and Mental Health 12 (4): 434-443.

Ory, M., Hoffman, R., Yee, J., Tennstedt, S. and Schulz, R. (1999) Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. The Gerontologist 39 (2): 177-185.

Ostman, M. and Kjellin, L. (2002) Stigma by association. British Journal of Psychiatry 181 (6): 494-498.

Outhwaite, W. (1998) Naturalisms and anti-naturalism In: May, T. and Williams, M. (eds) Knowing the Social World. Buckingham: Open University Press.

Papastavrou, E., Kalokerinou, A., Papacostas, S., Tsangari, H. and Panagiota, S. (2007) Caring for a relative with dementia: family caregiver burden. Journal of Advanced Nursing 58 (5): 446-457.

Parahoo, K. (2006) Nursing Research Principles, Process and Issues. 2nd Edition. Basingstoke: Palgrave Macmillan.

Parker, I. (1999) Critical reflexive humanism and critical constructionist psychology In: Nightingale, D. and Cromby, J. (eds) Social Constructionist Psychology: A Critical Analysis of Theory and Practice. Buckingham: Open University Press.

Parker, S. and Lawton, D. (1994) Different Types of Care, Different Types of Carer. Evidence from the General Household Survey. London: HSMO.

Parnis, D., Mont, J. and Gombay, B. (2005) Cooperation of co-option? Assessing the methodological benefits and barriers involved in conducting qualitative research through medical institutions. Qualitative Health Research 15 (5): 686-697.

Parsons, K. (1997) The male experience of caregiving for a family member with Alzheimer's disease. Qualitative Health Research 7 (3): 391-407.

Parton, N. (2003) Rethinking professional practice: the contributions of social constructionism and the feminist 'ethics of care'. British Journal of Social Work 33 (1): 1-16.

Pastios, D. and Davey, A. (2005) Formal and informal community care for older adults In: Johnson, M. (ed) The Cambridge Handbook of Age and Ageing. Cambridge: Cambridge University Press.

Pearlin, L., Harrington, C., Powell Lawton, M., Montgomery, R. and Zarit, S. (2001) An overview of the social and behavioural consequences of Alzheimer's disease. Journal of Aging and Mental Health 5 (Supplement 1): S3-S6.

Pearlin, L., Mullan, J., Semple, S. and Skaff, M. (1990) Caregiving and the stress process: an overview of concepts and their measures. The Gerontologist 30 (5): 583-594.

Penn, D.L., Kommana, S., Mansfield, M. and Link, B.G. (1999) Dispelling the stigma of schizophrenia: II. The impact of information on dangerousness. Schizophrenia Bulletin. 25 (3): 437-446.

Perron, A., Rudge, T. and Holmes, D. (2010) Citizen minds, citizen bodies: the citizenship experience and the government of mentally ill persons. Nursing Philosophy 11 (2): 100-111.

Perry, J. (2002) Wives giving care to husbands with Alzheimer's disease: a process of interpretive caring. Research in Nursing and Health 25 (4): 307-316.

Perry, J. and O'Connor, D. (2002) Preserving personhood: (re)membering the spouse with dementia. Family Relations 51 (1): 55-62.

Pesut, B. and Johnson, J. (2007) Reinstating the 'Queen': understanding philosophical inquiry in nursing. Journal of Advanced Nursing 61 (1): 115-121.

Philips, S. (2007) Care. Cambridge: Polity.

Phinney, A. (2008) Towards understanding subjective experiences of dementia In: Downs, M. and Bowers, B. (eds) Excellence in Dementia Care. Research into Practice. Maidenhead: McGraw-Hill/Open University.

Pinquart, M. and Sorenson, S. (2003) Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: a meta analysis. Journal of Gerontology: Psychological Sciences and Social Sciences 58B (2): 112-128.

Pinquart, M. and Sorenson, S. (2006) Gender differences in caregiver stressors, social resources and health: an updated meta-analysis. Journal of Gerontology: Psycological Sciences and Social Sciences 61b (1): 33-45.

Pollitt, P. (1994) The meaning of dementia to those involved as carers In: Huppert, F., Brayne, C. and O'Connor, D. (eds) Dementia and Normal Aging. Cambridge: Cambridge Unviersity Press.

Population Health Directorate (2008) Health Status of the Population of Ireland. Naas: Health Services Executive.

Post, S. (2000a) Concepts of Alzheimer's disease in a hypercognitive society In: Whitehouse, P., Maurier, K. and Ballenger, J. (eds) Conceptions of Alzheimer's Disease: Biological, Clinical and Cultural Perspectives. Baltimore, MD: Johns Hopkins University Press.

Post, S. (2000b) The Moral Challenge of Alzheimer Disease 2nd Edition. Baltimore: The John Hopkins Univeristy Press.

Post, S. (2001) Comments on research in the social sciences pertaining to Alzheimer's disease: a more humble approach. Aging and Mental Health 5 (Supplement 1): S17-S19.

Potter, J. and Wetherell, M. (1987) Discourse and Social Psychology: Beyond Attitudes and Behaviour. London: Sage.

Powell, J. (2009) Social theory, aging and health and welfare professionals: a foucauldian "toolkit". Journal of Applied Gerontology 28 (6): 669-682.

Powell Lawton, M., Moss, M., Hoffman, C. and Perkinson, M. (2000) Two transitions in daughters' caregiving careers. The Gerontologist 40 (4): 437-448.

Powell Lawton, M., Moss, M., Kleban, M., Glicksman, A. and Rovine, M. (1991) A two-factor model of caregiving appraisal and psychological well-being. Journal of Gerontology 46 (4): 181-189.

Pretorius, C., Walker, S. and Heyns, P.M. (2009) Sense of coherence amongst male caregivers in dementia. Dementia 8 (1): 79-94.

Price, B. (2002) Laddered questions and qualitative data research interviews. Journal of Advanced Nursing 37 (3): 273-281.

Price, B. (2004) Conducting sensitive patient interviews. Nursing Standard 18 (38): 445-452, 454-455.

Prior, L., Wood, F., Lewis, G. and Pill, R. (2003) Stigma revisited, disclosure of emotional problems in primary care consultation in Wales. Social Science and Medicine 56 (10): 2191-2200.

Q S R International Pty Ltd (2006) NVivo7. Doncaster Victoria: QSR International Pty Ltd.
Quayhagen, M. and Quaghagen, M. (1988) Alzheimer's stress: coping with the caregiving role. The Gerontologist 28 (3): 391-396.

Rager, K. (2005) Compassion stress and the qualitative researcher. Qualitative Health Research 15 (3): 423-430.

Raina, P., McIntyre, C., Zhu, B., McDowell, I., Santaguida, L., Kristjansson, B., Hendricks, A., Massfeller, H. and Chambers, L. (2004) Understanding the influence of the complex relationships among informal and formal supports on the well-being of caregivers of persons with dementia. Canadian Journal of Aging 23 (Supplement): S43-S53.

Rapp, S. and Chao, D. (2000) Appraisals of strain and of gain: effects on psychological wellbeing of caregivers of dementia patients. Aging and Mental Health 4 (2): 142-147.

Raschick, M. and Ingersoll-Dayton, B. (2004) The costs and rewards of caregiving among aging spouses and adult children. Family Relations 53 (3): 317-325.

Ray, M. (1994) The richness of phenomenology: philosophic, theoretic, and methodological concerns In: Morse, J. (ed) Critical Issues in Qualitative Research. Thousand Oaks, CA: Sage Publications.

Ray, M., Bernard, M. and Philips, J. (2009) Critical Issues in Social Work with Older People. Basingstoke: Palgrave MacMillan.

Reidpath, D., Chan, K., Gifford, S. and Allotey, P. (2005) He hath the French pox: stigma, social value and social exclusion. Sociology of Health and Illness 27 (4): 468-489.

Rennie, D. (1998a) Grounded theory methodology. The pressing need for a coherent logic of justification. Theory and Psychology 8 (1): 101-119.

Rennie, D. (1998b) Reply to Corbin. From one interpreter to another. Theory and Psychology 8 (1): 129-135.

Robertson, A. (1991) The politics of Alzheimer's disease: a case study in apocalyptic demography. In: Minkler, M. and Estes, C.L. (eds) Critical Perspectives on Aging. New York Baywood Publishing.

Robrecht, L. (1995) Grounded theory: evolving methods. Qualitative Health Research 5 (2): 169-177.

Rogero-Garcia, J., Prieto-Flores, M.E. and Rosenberg, M.W. (2008) Health services use by older people with disabilities in Spain: do formal and informal care matter? Ageing and Society 28 (7): 959-978.

Rolfe, G. (2006a) Validity, trustworthiness and rigour: quality and the idea of qualitative research. Journal of Advanced Nursing 53 (3): 304-310.

Rolfe, G. (2006b) Judgements without rules: towards a postmodern ironist concept of research validity. Nursing Inquiry 13 (1): 7-15.

Rolland, J.S. (1994) Families, Illness and Disability: an Integrative Treatment Model. New York: Basic Books.

Rorty, R. (1979) Philosophy and the Mirror of Nature. Princeton, NJ: Princeton University Press.

Rosenberg, C. (1992) Introduction. Framing disease: illness, society, and history In: Rosenberg, C. (ed) Framing Disease. New Brunswick, New Jersey: Routledge University Press.

Rubin, H.J. and Rubin, I.S. (1995) Qualitative Interviewing: The Art of Hearing Data. Thousand Oaks: Sage Publications.

Ryan, T., Nolan, M., Reid, D. and Enderby, P. (2008) Using the senses framework to acheive relationship-centred dementia care services: a case example. Dementia 7 (1): 71-93.

Sabat, S. (2001) The Experience of Alzheimer's Disease: Life Through a Tangled Web. Oxford and Malden, Massachusetts: Blackwell.

Sabat, S. and Harre, R. (1992) The construction and deconstruction of self in Alzheimer's disease. Ageing and Society 12 (4): 443-461.

Sahin, H.A., Gurvit, H., Emre, M., Hanagasi, H.A., Bilgic, B. and Harmanci, H. (2006) The attitude of elderly lay people towards the symptoms of dementia. International Psychogeriatrics 18 (2): 1-8.

Sandberg, J. and Erkisson, H. (2009) From alert commander to passive spectator: older male carers' experience of receiving formal support. International Journal of Older People Nursing 4 (1): 33-40.

Sandelowski, M. (1986) The problem of rigor in qualitative research. Advances in Nursing Science 8 (3): 27-37.

Sandelowski, M. (1993) Rigor or rigor mortis: The problem of rigor in qualitative research. Advances in Nursing Science 16 (2): 1-8.

Sandelowski, M. (2006) "Meta-jeopardy": the crisis of representation in qualitative metasynthesis. Nursing Outlook 54 (1): 10-16.

Sandelowski, M. and Barroso, J. (2002) Reading qualitative studies. International Journal of Qualitative Methods. 1 (1). (online) Available: http://www/ualberta.ca~ijqm/ (13th April 2009).

Sargent, J., Williams, R., Hagerty, B., Lynch-Sauer, J. and Hoyle, K. (2002) Sense of belonging as a buffer against depressive symptoms. Journal of the American Psychiatric Nurses Association 8 (4): 120-129.

Sartorius, N. (1998) Stigma: what can psychiatrists do about it? The Lancet 352 (9133): 1058.

Saussure de, E. (1974) Course in general linguistics. London: Fontana.

Sayce, L. (2000) From Psychiatric Patient to Citizen: Overcoming Discrimination and Social Exclusion. London: Macmillan Press.

Scambler, G. (2009) Health-related stigma. Sociology of Health and Illness 31 (3): 441-455.

Scholl, J.M. and Sabat, S.R. (2008) Stereotypes, stereotype threat and ageing: implications for the understanding and treatment of people with Alzheimer's disease. Ageing and Society 28 (1): 103-130.

Schulz, R. and Martire, L. (2004) Family caregiving of persons with dementia. American Journal of Geriatric Psychiatry 12 (3): 240-249.

Schulz, R., O'Brien, A.T., Bookawala, J. and Fleissener, K. (1995) Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates and causes. The Gerontologist 35 (6): 771-791.

Schutz, A. (1972) Concept and theory formation in the social sciences In: Emmet, D. and MacIntyre, A. (eds) Sociological Theory and Philosophical Analysis. London: Macmillan.

Schwandt, T. (2003) Three epistemological stances for qualitative inquiry: interpretivism, hermeneutics and social constructionism In: Denzin, N. and Lincoln, Y. (eds) The Landscape of Qualitative Research Theories and Issues. 2nd Edition. Thousand Oaks: Sage Publications.

Scott, S. (2009) Making Sense of Everyday Life. Cambridge: Polity.

Sevenhuijsen, S. (2000) Caring the third way: the relation between obligation, responsibility and care in the *Third Way* discourse. Critical Social Policy 20 (1): 5-37.

Sevenhuijsen, S. (2003) The place of care: the relevance of the feminist ethic of care for social policy. Feminist Theory 4 (2): 179-197.

Sevick, M., McConnell, T. and Muender, M. (2003) Conducting research related to treatment of Alzheimer's disease: ethical issues, cognitive impairment and the progressive nature of Alzheimer's disease can make researching a cure even more complicated. Journal of Gerontological Nursing 29 (2): 6-12.

Shanks-McElroy, H. and Strobino, J. (2001) Male carergivers of spouses with Alzheimer's disease: risk factors and health status. American Journal of Alzheimer's Disease and Other Dementias 16 (3): 167-175.

Shotter, J. (1989) Social accountability and the social construction of 'you' In: Shotter, J. and Gergen, K. (eds) Texts of Identity. London: Sage Publications.

Skaff, M. and Pearlin, L. (1992) Caregiving: role engulfment and the loss of self. The Gerontologist 32 (5): 656-664.

Smith, D. (1990) Texts, Facts, and Feminity. Exploring the Relations of Ruling. London: Routledge.

Smith, M. (1998) Social Science in Question. London: Sage Publications.

Snowdon, D. (2001) Aging with Grace. New York: Bantam Books.

Snyder, L. (2006) Personhood and interpersonal communication in dementia In: Hughes, J., Louw, S. and Sabat, S. (eds) Dementia. Mind, Meaning and the Person. Oxford: Oxford University Press.

Son, J., Erno, A., Shea, D., Femia, E., Zarit, S. and Parris Stephens, M.A. (2007) The caregiver stress process and health outcomes. Journal of Aging and Health 19 (6): 871-887.

Sontag, S. (1991) Illness as Metaphor and Aids as Metaphor. London: Penguin Books.

Stam, H.J. (2001) Introduction: social constructionism and its critics. Theory and Psychology 11 (3): 291-296.

Stanley, L. and Wise, S. (1983) Breaking Out: Feminist Consciousness and Feminist Research. London: Routledge and Kegan Paul.

Stephan, B. and Brayne, C. (2008) Prevalence and projections of dementia In: Downs, M. and Bowers, B. (eds) Excellence in Dementia Care. Research into Practice. Maidenhead: McGraw-Hill/Oxford University Press.

Stern, P.N. (1994) The grounded theory method: its uses and processes In: Glaser, B. (ed) More Grounded Theory Methodology: a Reader. Mill Valley: Sociology Press.

Stout, P., Villegas, J. and Jennings, N. (2004) Images of metnal illness in the media: identifying gaps in the research. Schizophrenia Bulletin 30 (3): 543-561.

Strauss, A. and Corbin, J. (1990) Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. London: Sage.

Strauss, A. and Corbin, J. (1998) Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. 2nd Edition. Thousands Oaks, CA: Sage.

Svanstrom, R. and Dahlberg, K. (2004) Living with dementia yields a heteronomous and lost existence. Western Journal of Nursing Research 26 (6): 671-667.

Sweeting, H. and Gilhooly, M. (1997) Dementia and the phenomenon of social death. Sociology of Health and Illness 19 (1): 93-117.

Tarlier, D. (2005) Mediating the meaning of evidence through epistemological diversity. Nursing Inquiry 12 (2): 126-134.

Taylor, R. (2007) Alzheimer's from the Inside Out. Baltimore: Health Professions Press.

The Carers Association (2008) Listen to Carers. Report on a Nation-wide Carer Consultation. Dublin: The Carers Assoication.

The United States Department of Health and Human Services (1999) Mental Health - a Report of the Surgeon General - Executive Summary. Rockville MD: U.S. Department of Health and Human Services. Substance Abuse and Mental Health Services Administration, Centre for Metnal Health Services, National Institutes of Health, National Institute of Mental Health.

Thomas, P., Lalloue, F., Preux, P.M., Hazif-Thomas, C., Pariel, S., Inscale, R., Belmin, J. and Clement, J.P. (2006) Dementia patients caregivers quality of life: the PIXEL study. International Journal of Geriatric Psychiatry 21 (1): 50-56.

Thompson, R., Lewis, S., Muprhy, M., Hale, J., Blackwell, P., Acton, G., Clough, D., Patrick, G. and Bonner, P. (2004) Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? Biological Research for Nursing 5 (4): 319-330.

Thorne, S. and Darbyshire, P. (2005) Land mines in the field: a modest proposal for improving the craft of qualitative health research. Qualitative Health Research 15 (8): 1105-1113.

Timonen, V. (2008) Ageing Societies: A Comparative Introduction. Maidenhead: Open University Press.

Tobin, G. and Begley, C. (2004) Methodological rigor within a qualitative framework. Journal of Advanced Nursing 48 (4): 388-396.

Toffoli, L. and Rudge, T. (2006) Organizational predicaments: ethical conditions for nursing research. Journal of Advanced Nursing 56 (6): 600-606.

Townsend, K. and McWhirter, B. (2005) Connectedness: a review of the literature with implications for counseling, assessment and research. Journal of Counseling and Development 83 (2): 191-201.

Tregaskis, C. (2004) Constructions of Disability. Researching the Interface Between Disabled and Non-disabled People. London: Routledge

Twig, J. and Atkin, K. (1994) Carers Perceived: Policy and Practice in Informal Care. Buckingham: Open University Press.

Ulstein, I., Bruun Wyller, T. and Engedal, K. (2007) The relative stress scale, a useful instrument to identify aspects of carer burden in dementia? International Journal of Geriatric Psychiatry 22 (1): 61-67.

United Nations Programme on Ageing and The International Association of Gerontology and Geriatrics (2007) Research Agenda on Ageing for the 21st Century. 2007 Update. New York: United Nations Programme on Ageing and The International Association of Gerontology and Geriatrics.

Usher, K. and Arthur, D. (1998) Process consent: a model for enhancing informed consent in mental health nursing. Journal of Advanced Nursing 27 (4): 692-697.

Vedhara, K., Shanks, N., Anderson, S. and Lightman, S. (2000) The role of stressors and psychosocial variables in the stress process: a study of chronic caregiver stress. Psychosomatic Medicine 62 (3): 374-385.

Vellone, E., Piras, G., Talucci, C. and Cohen, M.Z. (2008) Quality of life for caregivers of people with Alzheimer's disease. Journal of Advanced Nursing 61 (2): 222-231.

Vernooij-Dassen, M., Moniz-Cook, E.D., Woods, R.T., De Lepeleire, J., Leuschner, A., Zanetti, O., de Rotrou, J., Kenny, G., Franco, M., Peters, V., Iliffe, S. and The Interdem group (2005) Factors affecting timely recognition and diagnosis of dementia across Europe: from awareness to stigma. International Journal of Geriatric Psychiatry 20 (4): 377-386.

Victor, C. (2005) The Social Context of Ageing. A Textbook of Gerontology. Abingdon: Routledge.

Vikstrom, S., Josephson, S., Stigsdotter-Neely, A. and Nygard, L. (2008) Engagement in activities: experiences of persons with dementia and their caregiving spouses. Dementia 7 (2): 251-270.

Vincent, J. (2008) The cultural construction of old age as a biological phenomenon: science and anti-ageing technologies. Journal of Aging Studies. 22 (4): 331-339.

Vitaliano, P., Russo, J. and Niauro, R. (1995) Plasma lipids and their relationships with psychosocial factors in older adults. Journal of Gerontology 50 (1): 18-24.

Vitaliano, P., Zhang, J. and Scanlan, J. (2003) Is caregiving hazardous to one's physical health? A meta-analysis. Psychological Bulletin 129 (6): 946-972.

Wahl, O.F. (1992) Mass media images of mental illness: a review of the literature. Journal of Community Psychology 20 (4): 343-352.

Wahl, O.F., Wood, A. and Richards, R. (2002) Newspaper coverage of mental illness: Is it changing? Psychiatric Rehabilitation Skills 6 (1): 9-31.

Walker, A., Pratt, C. and Eddy, L. (1995) Informal caregiving to aging family members. Family Relations 44 (4): 402-411.

Ward-Griffin, C. (2008) Health professionals caring for aging relatives. Negotiating the public-private boundary. In: Martin-Matthews, A. and Philips, J. (eds) Aging and Caring at the Intersection of Work and Home Life. New York: Lawrence Erlbaum Associates. Taylor Francis Group.

Ward-Griffin, C. and Marshall, V. (2003) Reconceptualizing the relationship between "public" and "private" eldercare. Journal of Aging Studies 17 (2): 189-208.

Ward-Griffin, C., Oudshoorn, A., Clark, K. and Bol, N. (2007) Mother-adult-daughter relationships within dementia care: a critical analysis. Journal of Family Nursing 13 (1): 13-32.

Wasserman, J.A., Clair, J.M. and Wilson, K. (2009) Problematics of grounded theory: innovations for developing an increasingly rigorous qualitative method. Qualitative Research 9 (3): 355-381.

Weaver, K. and Olson, J. (2006) Understanding paradigms used for nursing research. Journal of Advanced Nursing 53 (4): 459-469.

Weaver Moore, L. and Miller, M. (1999) Initiating research with doubly vulnerable populations. Journal of Advanced Nursing 30 (4): 1034-1040.

Weinberg, D. (2008) The philosophical foundations of constructionist research In: Handbook of Constructionist Research. New York: The Guilford Press.

Werner, P., Goldstein, D. and Buchbinder, E. (2010) Subjective experience of family stigma as reported by children of Alzheimer's disease patients. Qualitative Health Research. 20 (2): 159-169.

Westerhof, G. and Tulle, E. (2007) Meanings of ageing and old age: discursive contexts, social attitudes and personal identities In: Bond, J., Peace, S., Dittmann-Kohli, F. and Westerhof, G. (eds) Ageing in Society. 3rd Edition. London: Sage Publications.

Wetherell, M. (2001) Themes in discourse research In: Wetherell, M., Yates, S. and Taylor, S. (eds) Discourse Theory and Practice: a Reader. London: Sage.

Whitehouse, P. and George, D. (2008) The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis. New York: St Martin's Press.

Whittemore, R., Chase, S. and Mandle, C. (2001) Validity in Qualitative Research. Qualitative Health Research 11 (4): 522-537.

Wiersma, E. (2008) The experiences of place: veterans with dementia making meaning of their environments. Health & Place 14 (4): 779-794.

Wiles, J. (2005) Conceptualising place in the care of older people: the contributions of geographical terminology. International Journal of Older People Nursing 14 (8b): 100-108.

Wilkinson, T.M. (2001) Research, informed consent, and the limits of disclosure. Bioethics 15 (4): 341-363.

Wilkins, V., Bruce, M. and Sirey, J.A. (2009) Caregiving tasks and training interest of family caregivers of medically ill homebound older adults. Journal of Aging and Health 21 (3): 528-542.

Williams, M. and May, T. (1996) Introduction to the Philosophy of Social Research. London: University College London.

Willig, C. (1999) Beyond appearances: a critical realist approach to social constructionist work In: Nightingale, D. and Cromby, J. (eds) Social Constructionist Psychology: a Critical Analysis of Theory and Practice. Buckingham: Open University Press.

Willig, C. (2001) Introducing Qualitative Research in Psychology: Adventures in Theory and Method. Buckingham: Open Unversity Press.

Willoughby, J. and Keating, N. (1991) Being in control: the process of caring for a relative with Alzheimer's disease. Qualitative Health Research 1 (1): 27-50.

Wilson, H. (1989a) Family caregiving for a relative with Alzheimer dementia: coping with negative choices. Nursing Research 38 (2): 94-98.

Wilson, H. (1989b) Family caregivers: the experience of Alzheimer's disease. Applied Nursing Research 2 (1): 40-45.

Wimo, A., Winbald, B. and Grafstrom, M. (1999) The social consequences for families with Alzheimer's disease patients: potential impact of new drug treatment. International Journal of Geriatric Psychiatry 14 (5): 338-347.

Wimpenny, P. and Gass, J. (2000) Interviewing in phenomenology and grounded theory: is there a difference? Journal of Advanced Nursing 31 (6): 1484 – 1492.

Wise, S. (1987) A framework for discussing ethical issues in feminist research: a review of the literature In: Stanley, L. and Scott, S. (eds) Writing Feminist Biography 2: Using Life Histories. Studies in Sexual Politics. 19. Manchester: Department of Sociology, University of Manchester.

Witucki Brown, J., Chen, S.L., Mitchell, C. and Province, A. (2007) Help-seeking by older husbands caring for wives with dementia. Journal of Advanced Nursing 59 (4): 352-360.

Woods, L. (2003) Grounded theory explained. Nurse Researcher 11 (2): 4-6.

Woods, L., Priest, H. and Roberts, P. (2002) An overview of three different approaches to the interpretation of qualitative data. Part 2: practical illustrations. Nurse Researcher 10 (1): 43-51.

Woodward, V. (1997) Professional caring: a contradiction in terms? Journal of Advanced Nursing 26 (5): 999-1004.

Wright Mills, C. (1963) Power, Politics and People: The Collected Essays of C. Wright Mills. New York: Basic Books.

Wuest, J., King Ericson, P. and Noerager Stern, P. (1994) Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. Journal of Advanced Nursing 20 (3): 437-443.

Yang, L.H., Kleinman, A., Link, B.G., Phelan, J., Lee, S. and Good, B. (2007) Culture and stigma: adding moral experience to stigma theory. Social Science and Medicine 63 (7): 1524-1535.

Yates, M.E., Tennstedt, S. and Chang, B. (1999) Contributers to and mediators of psychological well-being for informal caregivers. The Journals of Gerontology: Psychological Sciences and Social Sciences 54B (1): 12-22.

Zabalegui, A., Bover, A., Rodriquez, E., Cabrera, E., Diaz, M., Gallart, A., Gonza.ez, A., Gual, P., Izquierdo, M., Lopex, L., Pulpon, A. and Ramirez, A. (2008) Informal caregiving: perceived needs. Nursing Science Quarterly 21 (2): 166-172.

Zanetti, O., Frisoni, G., Bianchetti, A., Tamanza, G., Cogoli, V. and Trabucchi, M. (1998) Depressive symptoms of Alzheimer caregivers are mainly due to personal rather than patient factors. International Journal of Geriatric Psychiatry 13 (6): 358-367.

Zarit, S., Orr, N.K. and Zarit, J.M. (1985) The Hidden Victims of Alzheimer's Disease: Families Under Stress. Irvington, New York: New York University Press.

Zarit, S.H. and Gaugler, J. (2006) Care by families for late stage dementia In: Burns, A. and Winbald, B. (eds) Severe Dementia. Chichester: John Wiley and Sons.

Zarit, S.H. and Leitsch, A. (2001) Developing and evaluating community based intervention programmes for Alzheimer's patients and their caregivers. Aging and Mental Health 5 (Supplement 1): S84-S98.

Zarit, S.H., Reever, K. and Bach-Peterson, J. (1980) Relatives of impaired elderly: correlates of feelings of burden. The Gerontologist 20 (6): 649-655.

Zhang, J., Vitaliano, P. and Lin, H.H. (2006) Relations of caregiving stress and health depend on the health indicators used and gender. International Journal of Behavioral Medicine 13 (2): 177-181.

Zhu, C., Moore, M. and Clipp, E. (2003) Demetnia problem behaviour and the production of informal caregiving services. Review of Economics of the Household 1 (1/2): 59-76.

Zhu, C., Scarmeas, N., RTorgan, R., Albert, M., Brandt, J., Blacker, D., Sano, M. and Stern, Y. (2006) Longitudinal study of effects of patient characteristics on direct costs in Alzheimer disease. Neurology 67 (6): 998-1005.

Appendix 1 Study Inclusion Criteria

You are invited to participate in this study if you:

Persons with dementia

- Have dementia
- Are willing to voluntarily participate in the study
- Understand the purpose and process of the research

Note: People with dementia are welcome to have an informal carer present during the interview.

Informal carers of persons with dementia

- Are caring for or have cared for a person with dementia
- Are willing to voluntarily participate in the study
- Understand the purpose and process of the research

Allied Health and Social Care Professionals

- Are an allied health professional with experience of caring for persons with dementia

Or

- Represent a disability organisation or other agency with knowledge and/or experience of stigma and/or dementia
- Are willing to voluntarily participate in the study
- Understand the purpose and process of the research

Appendix 2 Sample Letter of Invitation

Date:

RE : RESEARCH STUDY 'EXPLORING STIGMA AND DEMENTIA'

Dear Sir/Madam

I am writing to invite you to participate in the research study named above. You are invited to consider participating in this study because of your experiences of dementia or because you represent a disability organisation or other agency with knowledge and/or experience of stigma and/or dementia.

Please read the enclosed Information Sheet, which describes the nature and purpose of the study and what participation in the research would involve.

Should you wish to discuss participating in this study, please complete the second page of this letter and return it as soon as possible to the me in the envelope provided. I will then contact you to discuss participation and answer any questions you may have. Should you decide not to participate in this study, you will not be contacted further regarding this matter.

Yours sincerely,

____

Louise Nolan [Daly],
MSc/PhD Student,
School of Nursing and Midwifery,
Trinity College Dublin.

Exploring Stigma and Dementia

Name (Block Capitals): ______________________________

Please tick the appropriate box :

I am a Person with dementia : ☐

I am a Carer/family member : ☐

I am an Allied Health Professional/Person working in dementia care (please specify below): ☐

____

I represent a Disability organisation or other Agency (please specify below): ☐

____

I wish to be contacted to discuss participation in the study entitled: Exploring Stigma and Dementia.

I can be contacted at the following _____________________ telephone number. I understand that by agreeing to discuss the study with the Louise Nolan [Daly], I am not consenting to participate in the research.

Signature: ________________________

Appendix 3 Sample Study Information Sheet

1. Title of study:

EXPLORING STIGMA AND DEMENTIA

2. Introduction:

My name is Louise Nolan [Daly] and I am an MSc/PhD student in the School of Nursing and Midwifery, Trinity College Dublin. I have worked with people with dementia for a number of years and I am interested in understanding further what it is like to live with dementia. I am inviting you to participate in this study because of your experiences of dementia. The purpose of this study is to explore stigma and dementia and the impact on those affected, that is people with dementia and carer/family members.

3. Procedures: What will the study involve?

As a nurse with extensive experience in dementia care, I will meet with you for approximately one hour to talk about your experience of dementia. During the interview I will ask you to provide some general background information. You will then be asked to describe your experience/perceptions of dementia and stigma.

With your permission this conversation/interview will be audio-taped. After the interview the recording will be transcribed and analysed. The findings of the interviews will be combined in a report/thesis. This report may be submitted for publication and or presentation at a conference and may be the basis for the development of interventions to encourage a better understanding of dementia.

4. Who can participate in the study?

You are invited to participate in this study if you fulfil one of the following criteria:

- You are caring for or have cared for a person with dementia
- You are willing to voluntarily participate in the study
- You understand the purpose and process of the research

5. Benefits:

For you:

To date little is known from an Irish perspective about the experiences of persons with dementia, their carers, family members or health and social care professionals in relation to the concept of stigma. The possible benefits for you therefore relate to the value of telling your story, reflecting on your experiences/perceptions and the opportunity to discuss the subject with me as an interested researcher.

For dementia care:

This study will lead to enhanced knowledge and understanding of stigma in relation to dementia from an Irish perspective and may identify strategies to address stigma and areas requiring further research.

6. Risks:

There are no known risks to you if you choose to participate in this study. Sometimes however talking about dementia may be upsetting. Should you find this upsetting your wellbeing is a priority over the research study. We can stop the interview, can recommence at another time and/or I can connect you with supportive services available through the Alzheimer's Society of Ireland.

7. Exclusion from participation:

You cannot be in this study if any of the following are true:

- You have not cared for a person with dementia
- You are not willing to voluntarily participate in the study

8. Confidentiality:

All information collected in this study will be treated as confidential. Your identity will remain confidential. A code will be assigned to your interview. If you wish to do so, you may have access to your interview transcript. Your name will not be published and will not be disclosed to anyone outside the study group.

9. Compensation:

This study is covered by standard institutional indemnity insurance. Nothing in this document curtails your rights. There will be no payment for participation.

10. Voluntary Participation:

Your participation in this study is voluntary. You may withdraw at any time. If you decide not to participate, or if you withdraw, you will not be penalised and will not give up any benefits which you had before entering the study.

11. Who is supporting this Study?

The study has been approved by the Faculty of Health Sciences Ethics Committee, Trinity College Dublin.

12. Further information:

You can get more information or answers to your questions about the study, your participation in the study, and your rights, from me, Louise Nolan [Daly] MSc/PhD student. I can be telephoned at 01- 8963931 or e-mailed at nolanl1@tcd.ie. Alternatively, you can contact my PhD supervisor on this study, Prof Mary McCarron, at telephone extension number 01-8962694 or by e-mail at mccarrm@tcd.ie.

Appendix 4 Profile of Informal Carers by Age and Sex

Age	**Male**	**Female**
30-39	0	2
40-49	0	3
50-59	1	3
60-69	0	4
70-79	2	4
80-89	1	0
Total	4	16

Appendix 5 Informal carer relationship to the person with dementia

Relationship to the person with dementia	**Number of informal carer participants**
Wife	8
Husband	3
Daughter	8
Son-in-law	1

Appendix 6 Type of Dementia Diagnosis Reported by Informal Carers

Dementia type	Number of informal carers
Alzheimer’s disease	13
Vascular dementia	3
Fronto-temporal dementia	1
Unknown	3

Appendix 7 Length of time informal carers had been caring

Participant code	Total time caring (in years)
CFM1	8
CFM2	15
CFM3	3
CFM4	4
CFM5	5
CFM6	12
CFM7	8
CFM8	4
CFM9	7
CFM10	6
CFM11	5
CFM12	10
CFM13	4
CFM14	4
CFM15	5
CFM16	16
CFM17	10
CFM18	12
CFM19	7
CFM20	7
Total	**152**

Appendix 8 Services Accessed by Informal Carers

Service Type	Number of informal carers
Alzheimer Society of Ireland	20
Day care services	16
Medical Consultant (type not specified)	20
Carer coming in to the home (part or full time)	13
Respite services	13
Nursing home – public	4
Nursing home – private	2

Appendix 9 Profile of Allied Health and Social Care and Disability Organisation Professionals

Occupation	Years of specific dementia care experience
Social worker	14
Senior psychologist	1
Day care manager	7
Consultant geriatrician	20
General practitioner	30
Dementia home care co-ordinator	4.5
Dementia care co-ordinator	17
Social worker	20
Disability organization representative	Not applicable
Carer support resource	20
Total years dementia specific experience	133.5

Appendix 10 Background Information Sheet Informal Carers

Participant code: ____________________

Relationship to the person with dementia: ________________________________

Person with dementia: Alive ☐ **Deceased** ☐

Carer/family members's age: ____________

Gender: **Male** ☐ **Female** ☐

Where does the carer/family member live? **Urban** ☐ **Rural** ☐

Is the carer/family member living with the person with dementia?
Yes ☐ **No** ☐ **N/A** ☐

Is the person: **Single** ☐ **Married** ☐ **Widow** ☐ **Widower** ☐
Other _________________________

Children: **Yes** ☐ **No** ☐ **If yes, how many?** __________________

Length of time since relative/family member's diagnosis: _____________________

Type of dementia (if known): ____

Total number of years caring (to include time since admission to continuing care if applicable): _______________

Number of years full-time caring: ______________

Number of years part-time caring (excluding time since admission to continuing care if applicable): ______________

Is the carer working outside the home? **Yes** ☐ **No** ☐

Occupation: ______________________________

Services Accessed: ____

Appendix 11 Background Information Sheet for Persons with Dementia

Participant code: _______________

Participant's Age: _____________

Gender: **Male** ☐ **Female** ☐

Occupation/Previous Occupation: ______________________________________

Where does the person live?

Urban location ☐ **Rural location** ☐ **Living alone** ☐
Not living alone ☐

If not living alone, who is the person living with? __________________________

Is the person: **Single** ☐ **Married** ☐ **Widowed** ☐ **Widower** ☐

Other _________________________

Children: **Yes** ☐ **No** ☐

Who is the primary carer (e.g. spouse)______________________________

Is the primary carer living with the person with dementia:
Yes ☐ **No** ☐

Length of time since diagnosis: ______________________________

Type of dementia (if known)? ____

Services Accessed ____

Appendix 12 Background Information Sheet Allied Health, Social Care and Disability Professionals

Participant code:

Discipline (if appropriate) ____

Job Title ____

Type of organisation that participant represents (if appropriate):

____

Number of years working in dementia care (if appropriate): ______________

Appendix 13 Sample Interview Topic Guide

Preamble to the interview:

- Review the research purpose. Discuss the research interview and answer any participant questions. Complete participant consent form. Seek permission to record the interview and demonstrate how to turn off the recording device.

Potential topic guide (not all to be discussed):

- The dementia experience – participants story
- Resistance, adjustment, acceptance
- Effect on relationships, quality of life, feelings,
- Social outlets and belonging (before dementia and current)
- Disclosure
- Understanding of dementia – before/after diagnosis.
- Knowledge – how it is used, if/if not respected by others?
- Societal, media and close personal contacts perceptions of dementia and interactions with you/your family
- Coping mechanisms/strategies and/or caring for self?
- Concepts of protection and perception of threatened place
- Experiences of health and social care systems
- Sources of support / helping factors?
- The informal network – helping others?
- Self-perception/role – carer or extension of relational role, others view of you
- Things that cause you to take action on behalf of self or other
- Has your attitude to people with dementia changed as a result of your experiences?
- The future – yours and dementia care
- Do you feel stigma is/was an issue for you? OR Have you ever experienced stigma?

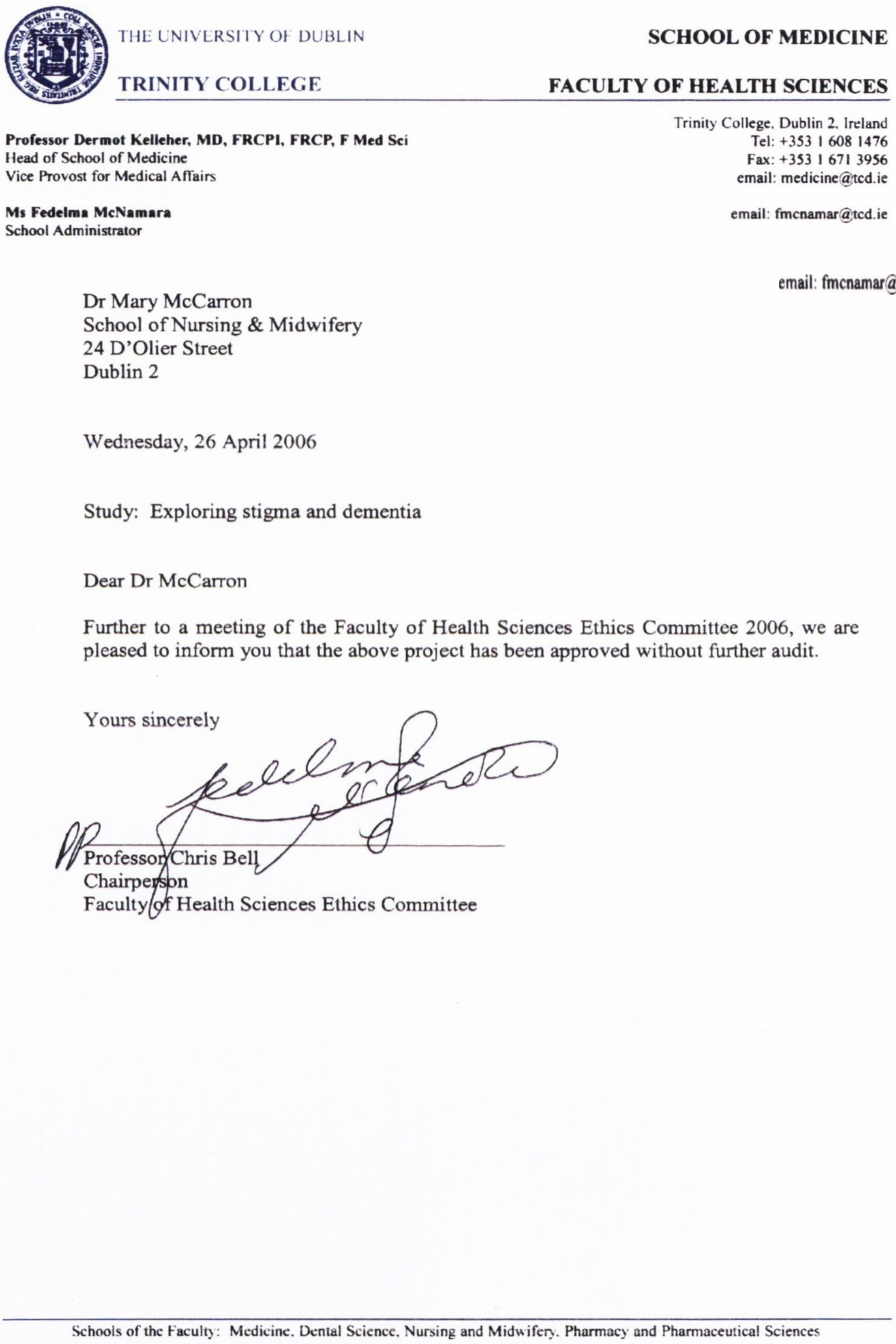
Examples of probes:

- Can you give me an example? Do you feel that is unique/typical?
- Can you tell me more about that?
- That's interesting, why did you do/say that?
- How did you feel?
- Use of silence
- What is this an example of? When does it happen? With whom? How? Under what conditions does it seem to occur? Why?
- With what consequences?

Conclusion to the interview:

- Explain how/when/where interview data will be stored and disposed of, potential supervisor access
- Answer any participant questions. Remind participant of contact details and that they can have a copy of the interview transcript if they wish.
- Check well-being & thank participants

Appendix 14 Letter of Ethical Approval for the Study



THE UNIVERSITY OF DUBLIN
TRINITY COLLEGE

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Professor Dermot Kelleher, MD, FRCPI, FRCP, F Med Sci
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Vice Provost for Medical Affairs

Ms Fedelma McNamara
School Administrator

email: fmcnamar@tcd.ie

email: fmcnamar@tcd.ie

Dr Mary McCarron
School of Nursing & Midwifery
24 D'Olier Street
Dublin 2

Wednesday, 26 April 2006

Study: Exploring stigma and dementia

Dear Dr McCarron

Further to a meeting of the Faculty of Health Sciences Ethics Committee 2006, we are pleased to inform you that the above project has been approved without further audit.

Yours sincerely

Professor Chris Bell
Chairperson
Faculty of Health Sciences Ethics Committee

Schools of the Faculty: Medicine, Dental Science, Nursing and Midwifery, Pharmacy and Pharmaceutical Sciences

Appendix 15 Reproduction of Letter to Update the Chairperson of the Ethics Committee

Dr Orla Shiels,
Faculty of Health Sciences Ethics Committee,
Trinity College Dublin.
3.07.07

RE: Exploring Stigma in Dementia

Dear Dr Sheils,

The above named study received ethical approval from the Faculty of Health Science Ethics Committee in April 2006. To date 23 interviews have been conducted with 24 participants and the findings thus far published in the following report,

Nolan, L., McCarron, M., McCallion, P. and Murphy-Lawless, J. (2006) Perceptions of Stigma in Dementia: an Exploratory Study. Dublin: The Alzheimer Society of Ireland.

We are writing to inform you that the study is continuing with the ongoing support of the Alzheimer Society of Ireland (please see accompanying letter). The nature and purpose of the study remains unchanged, as does the research approach being used to conduct it, i.e. grounded theory.

Yours sincerely,

______________________________.

Louise Nolan [Daly],
PhD Student,
School of Nursing and Midwifery,
Trinity College Dublin

______________________________.

Prof Mary McCarron,
Research Supervisor,
School of Nursing and Midwifery,
Trinity College Dublin.

Appendix 16 Reproduction of Letter of Support from the Alzheimer Society of Ireland

REMEMBER THOSE WHO CANNOT
THE ALZHEIMER
SOCIETY *of* IRELAND

Ms Louise Nolan
MSc/PhD student
School of Nursing and Midwifery
24 D'Olier Street
Dublin 2
Ireland
22-03-07

Dear Louise,

Thank you for your letter requesting the continued support from the Alzheimer Society of Ireland in relation to your research.

We are happy to continue our relationship with you and support the continuation of research into the area of stigma and dementia. We confirm that we can continue to act as gatekeepers in order to support the project. We understand that a different geographical area will be used and we can discuss this further before you begin to collect your data.

It is of course appropriate for you to provide information on the society, our helpline number or any other service information for respondents who may need support.

We look forward to increasing our knowledge on this extremely important area.

Yours sincerely

Maurice

Maurice O'Connell
C.E.O.

c.c. Dr Mary McCarron
Catherine Keogh/Grainne McGettrick

Alzheimer House, 43 Northumberland Avenue, Dun Laoghaire, Co. Dublin.
Phone: 01-284 6616 Fax: 01-284 6030 E-Mail: info@alzheimer.ie Website: www.alzheimer.ie
Registered in Ireland No. 102700 Registered Charity No. CHY 7868

Appendix 17 Participant Consent Form

TITLE OF THE RESEARCH STUDY:

EXPLORING STIGMA AND DEMENTIA

RESEARCHER'S CONTACT DETAILS:

Ms Louise Nolan [Daly], Telephone : 01 8963931 E-mail : nolanl1@tcd.ie

BACKGROUND AND PROCEDURES:

The purpose of this study is to explore stigma and dementia and the impact on all those affected. Participation will involve one interview. The interview will last approximately one hour and with your permission will be audio-taped. During the interview you will be asked to provide some general background information. You will then be asked to describe your experiences/perceptions of dementia and stigma. After the interview the recording will be transcribed and analysed. The findings of this research will be written up as a report and may be submitted for publication and/or presentation at a conference.

DECLARATION (Please read and tick if you agree):

I have read the study information sheet and this consent form. ☐

I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. ☐

I understand that all information collected in this study will be treated as confidential and that my identity will remain confidential. ☐

I understand that if I wish to do so, I may have access to my interview transcript. ☐

I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. ☐

I have received a copy of this agreement and I understand that the results of this research may be published. ☐

I understand I may withdraw from the study at any time. ☐

PARTICIPANT'S NAME (BlockCapitals):……………………………………………..

CONTACT NUMBER: ……………………………………………………………..

PARTICIPANT'S SIGNATURE:……………………………………………………..

Date:…………………………..

Statement of investigators responsibility: I have explained the nature and purpose of this study to the persons named above, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and have fully answered such questions. I believe that the person named above understood my explanation and has freely given informed consent.

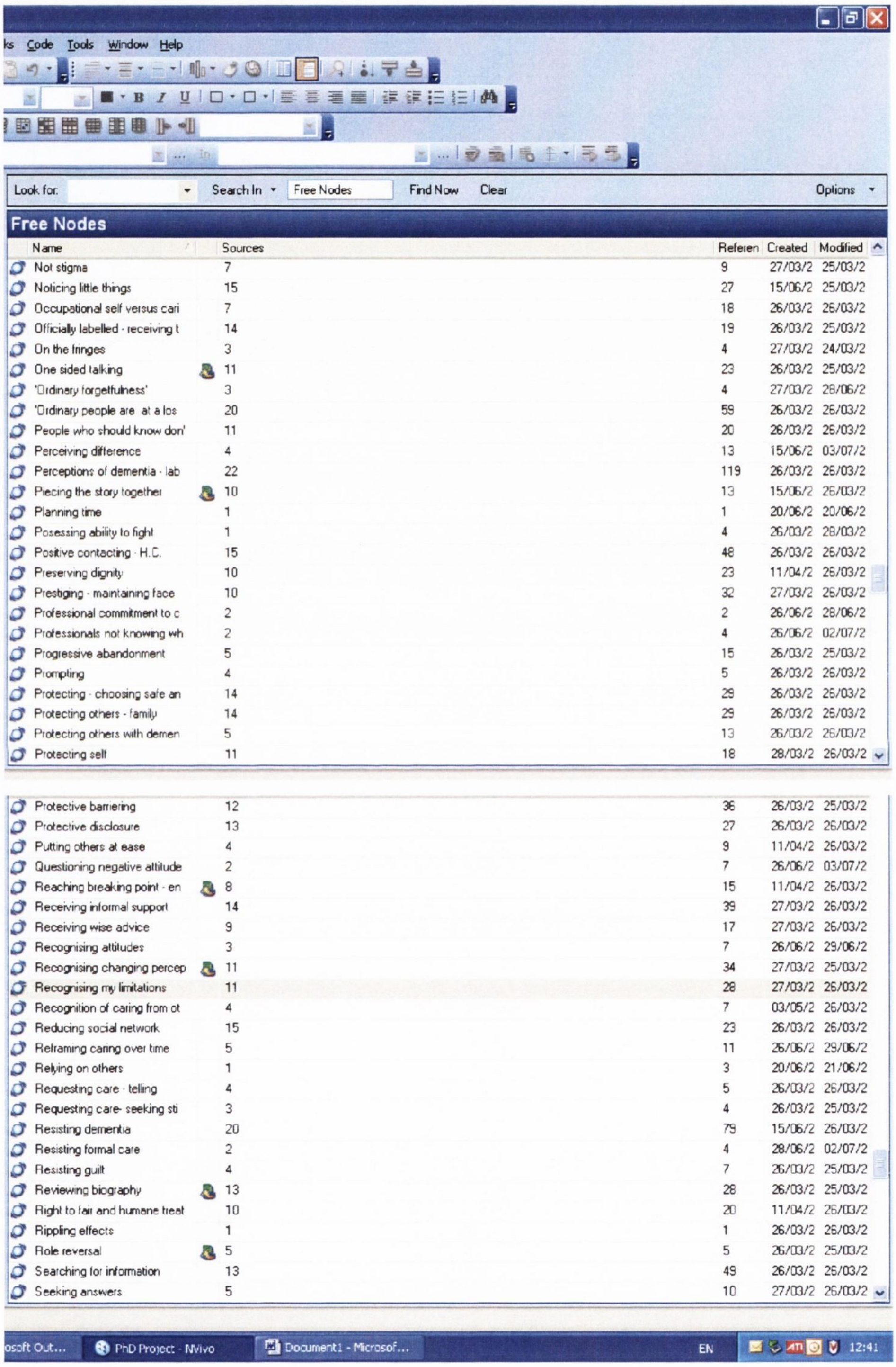
Investigators Signature

……………………………………………………………………

Date…………………………………………………

For Investigator's Use Only **Participant Code: ----------------**

Appendix 18 Sample of Open Codes (From No to Se)



Free Nodes

Name	Sources	Referen	Created	Modified
Not stigma	7	9	27/03/2	25/03/2
Noticing little things	15	27	15/06/2	25/03/2
Occupational self versus cari	7	18	26/03/2	26/03/2
Officially labelled - receiving t	14	19	26/03/2	25/03/2
On the fringes	3	4	27/03/2	24/03/2
One sided talking	11	23	26/03/2	25/03/2
'Ordinary forgetfulness'	3	4	27/03/2	28/06/2
'Ordinary people are at a los	20	59	26/03/2	26/03/2
People who should know don'	11	20	26/03/2	26/03/2
Perceiving difference	4	13	15/06/2	03/07/2
Perceptions of dementia - lab	22	119	26/03/2	26/03/2
Piecing the story together	10	13	15/06/2	26/03/2
Planning time	1	1	20/06/2	20/06/2
Posessing ability to fight	1	4	26/03/2	28/03/2
Positive contacting - H.C.	15	48	26/03/2	26/03/2
Preserving dignity	10	23	11/04/2	26/03/2
Prestiging - maintaining face	10	32	27/03/2	26/03/2
Professional commitment to c	2	2	26/06/2	28/06/2
Professionals not knowing wh	2	4	26/06/2	02/07/2
Progressive abandonment	5	15	26/03/2	25/03/2
Prompting	4	5	26/03/2	26/03/2
Protecting - choosing safe an	14	29	26/03/2	26/03/2
Protecting others - family	14	29	26/03/2	26/03/2
Protecting others with demen	5	13	26/03/2	26/03/2
Protecting self	11	18	28/03/2	26/03/2
Protective barriering	12	36	26/03/2	25/03/2
Protective disclosure	13	27	26/03/2	26/03/2
Putting others at ease	4	9	11/04/2	26/03/2
Questioning negative attitude	2	7	26/06/2	03/07/2
Reaching breaking point - en	8	15	11/04/2	26/03/2
Receiving informal support	14	39	27/03/2	26/03/2
Receiving wise advice	9	17	27/03/2	26/03/2
Recognising attitudes	3	7	26/06/2	29/06/2
Recognising changing percep	11	34	27/03/2	25/03/2
Recognising my limitations	11	28	27/03/2	26/03/2
Recognition of caring from ot	4	7	03/05/2	26/03/2
Reducing social network	15	23	26/03/2	26/03/2
Reframing caring over time	5	11	26/06/2	29/06/2
Relying on others	1	3	20/06/2	21/06/2
Requesting care - telling	4	5	26/03/2	26/03/2
Requesting care- seeking sti	3	4	26/03/2	25/03/2
Resisting dementia	20	79	15/06/2	26/03/2
Resisting formal care	2	4	28/06/2	02/07/2
Resisting guilt	4	7	26/03/2	25/03/2
Reviewing biography	13	28	26/03/2	25/03/2
Right to fair and humane treat	10	20	11/04/2	26/03/2
Rippling effects	1	1	26/03/2	26/03/2
Role reversal	5	5	26/03/2	25/03/2
Searching for information	13	49	26/03/2	26/03/2
Seeking answers	5	10	27/03/2	26/03/2

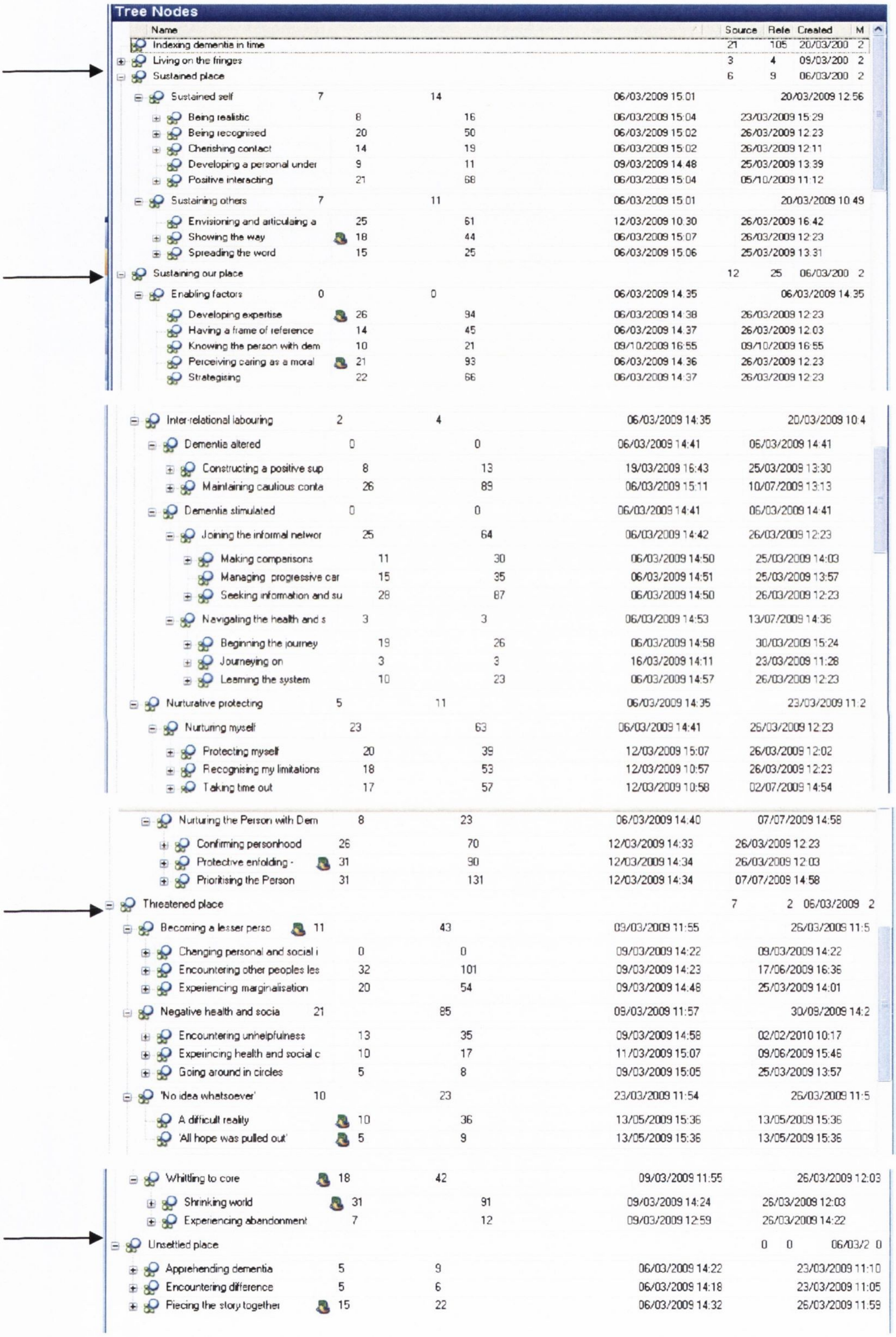
Appendix 19 Extract from Open Code List CFM12

Noticing changes
Emotionality
Indexing dementia events in time
Knowing others' wishes
Making healthcare decisions
First contacting
Being assessed
Being in denial
Sharing responsibility
Being diagnosed
Being labelled
Positive contacting
Being referred on
Delaying progression
Taking on a new role
Ethical caring
Being moved on
Surveilling
Encountering multiple healthcare professionals
Witnessing dehumanization

Right to fair and equitable treatment
Caring as an ethical way of being
Emotionality
Taking action
Seeking ethical care
Coping alone
Receiving helpful advice
Protecting other
Focusing on other
Being questioned by others
Preserving personhood
Making associations
Severed connections
Preserving/ respecting dignity of PWD
Reviewing biography
Respecting relationship with other
Dignity at risk
Negative encountering

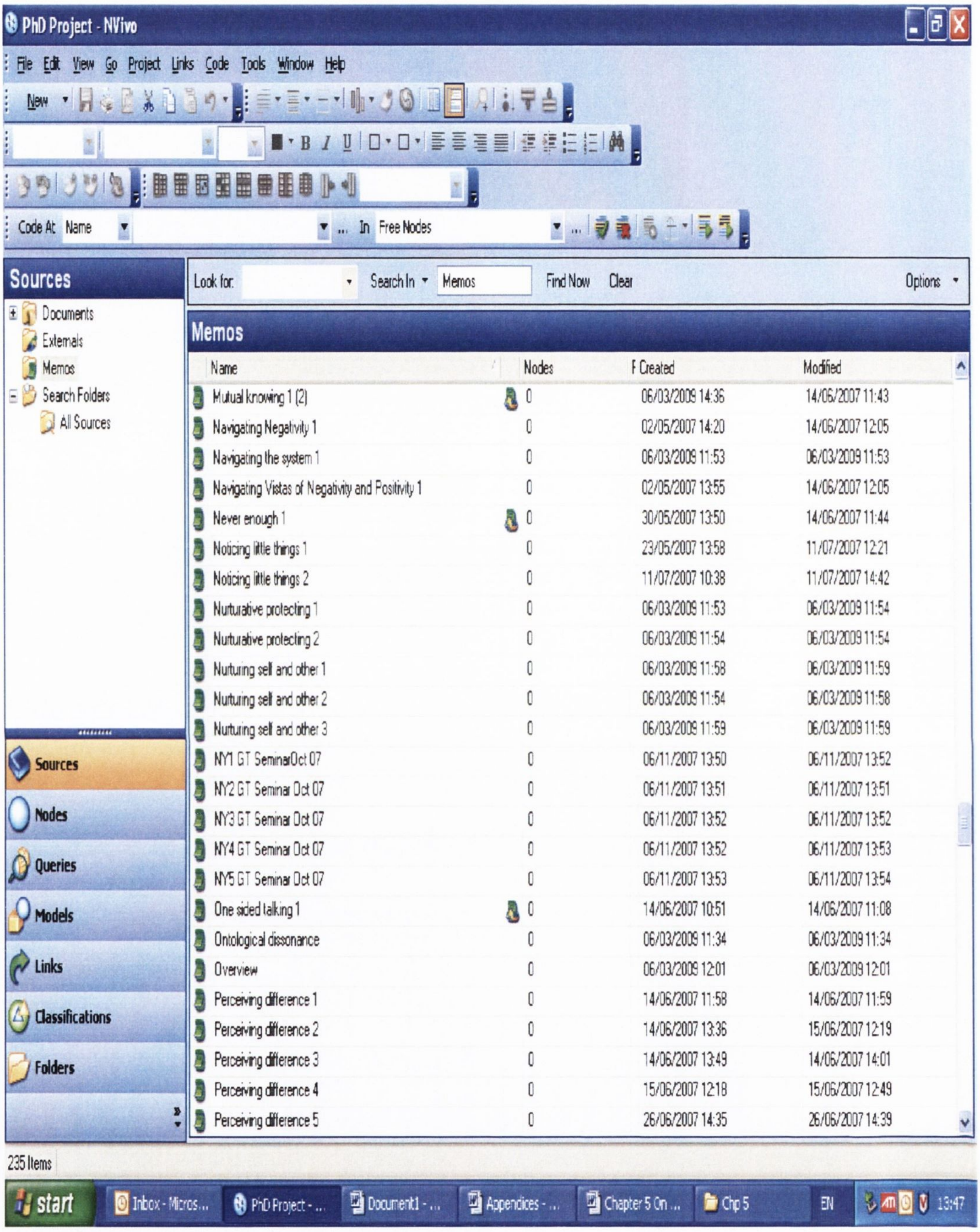
Maintaining other
Celebrating other
Protecting mother
Fighting for rights
Positive contacting
Negative encounters with others
Whittling to core
Being let down
Becoming increasingly socially isolated
Limited disclosure
Understanding others negative reactions
Being let down
Being afraid
One sided talking
Educating others
Strategising
Stigma
Negative family reactions
Being in denial
Severed contact

Appendix 20 Overview of the Coded Categorical Structure



Name	Source	Refe	Created	M
Indexing dementia in time	21	105	20/03/200	2
Living on the fringes	3	4	09/03/200	2
Sustained place	6	9	06/03/200	2
Sustained self	7	14	06/03/2009 15:01	20/03/2009 12:56
Being realistic	8	16	06/03/2009 15:04	23/03/2009 15:29
Being recognised	20	50	06/03/2009 15:02	26/03/2009 12:23
Cherishing contact	14	19	06/03/2009 15:02	26/03/2009 12:11
Developing a personal under	9	11	09/03/2009 14:48	25/03/2009 13:39
Positive interacting	21	68	06/03/2009 15:04	05/10/2009 11:12
Sustaining others	7	11	06/03/2009 15:01	20/03/2009 10:49
Envisioning and articulaing a	25	61	12/03/2009 10:30	26/03/2009 16:42
Showing the way	18	44	06/03/2009 15:07	26/03/2009 12:23
Spreading the word	15	25	06/03/2009 15:06	25/03/2009 13:31
Sustaining our place	12	25	06/03/200	2
Enabling factors	0	0	06/03/2009 14:35	06/03/2009 14:35
Developing expertise	26	94	06/03/2009 14:38	26/03/2009 12:23
Having a frame of reference	14	45	06/03/2009 14:37	26/03/2009 12:03
Knowing the person with dem	10	21	09/10/2009 16:55	09/10/2009 16:55
Perceiving caring as a moral	21	93	06/03/2009 14:36	26/03/2009 12:23
Strategising	22	66	06/03/2009 14:37	26/03/2009 12:23
Inter-relational labouring	2	4	06/03/2009 14:35	20/03/2009 10:4
Dementia altered	0	0	06/03/2009 14:41	06/03/2009 14:41
Constructing a positive sup	8	13	19/03/2009 16:43	25/03/2009 13:30
Maintaining cautious conta	26	89	06/03/2009 15:11	10/07/2009 13:13
Dementia stimulated	0	0	06/03/2009 14:41	06/03/2009 14:41
Joining the informal networ	25	64	06/03/2009 14:42	26/03/2009 12:23
Making comparisons	11	30	06/03/2009 14:50	25/03/2009 14:03
Managing progressive car	15	35	06/03/2009 14:51	25/03/2009 13:57
Seeking information and su	28	87	06/03/2009 14:50	26/03/2009 12:23
Navigating the health and s	3	3	06/03/2009 14:53	13/07/2009 14:36
Beginning the journey	19	26	06/03/2009 14:58	30/03/2009 15:24
Journeying on	3	3	16/03/2009 14:11	23/03/2009 11:28
Learning the system	10	23	06/03/2009 14:57	26/03/2009 12:23
Nurturative protecting	5	11	06/03/2009 14:35	23/03/2009 11:2
Nurturing myself	23	63	06/03/2009 14:41	26/03/2009 12:23
Protecting myself	20	39	12/03/2009 15:07	26/03/2009 12:02
Recognising my limitations	18	53	12/03/2009 10:57	26/03/2009 12:23
Taking time out	17	57	12/03/2009 10:58	02/07/2009 14:54
Nurturing the Person with Dem	8	23	06/03/2009 14:40	07/07/2009 14:58
Confirming personhood	26	70	12/03/2009 14:33	26/03/2009 12:23
Protective enfolding -	31	90	12/03/2009 14:34	26/03/2009 12:03
Prioritising the Person	31	131	12/03/2009 14:34	07/07/2009 14:58
Threatened place	7	2	06/03/2009	2
Becoming a lesser perso	11	43	09/03/2009 11:55	26/03/2009 11:5
Changing personal and social i	0	0	09/03/2009 14:22	09/03/2009 14:22
Encountering other peoples les	32	101	09/03/2009 14:23	17/06/2009 16:36
Experiencing marginalisation	20	54	09/03/2009 14:48	25/03/2009 14:01
Negative health and socia	21	85	09/03/2009 11:57	30/09/2009 14:2
Encountering unhelpfulness	13	35	09/03/2009 14:58	02/02/2010 10:17
Experincing health and social c	10	17	11/03/2009 15:07	09/06/2009 15:46
Going around in circles	5	8	09/03/2009 15:05	25/03/2009 13:57
'No idea whatsoever'	10	23	23/03/2009 11:54	26/03/2009 11:5
A difficult reality	10	36	13/05/2009 15:36	13/05/2009 15:36
'All hope was pulled out'	5	9	13/05/2009 15:36	13/05/2009 15:36
Whittling to core	18	42	09/03/2009 11:55	26/03/2009 12:03
Shrinking world	31	91	09/03/2009 14:24	26/03/2009 12:03
Experiencing abandonment	7	12	09/03/2009 12:59	26/03/2009 14:22
Unsettled place	0	0	06/03/2	0
Apprehending dementia	5	9	06/03/2009 14:22	23/03/2009 11:10
Encountering difference	5	6	06/03/2009 14:18	23/03/2009 11:05
Piecing the story together	15	22	06/03/2009 14:32	26/03/2009 11:59

Appendix 21 Sample of Memo Titles NVivo7 (From Mu to Pe)



Name	Nodes	Created	Modified
Mutual knowing 1 (2)	0	06/03/2009 14:36	14/06/2007 11:43
Navigating Negativity 1	0	02/05/2007 14:20	14/06/2007 12:05
Navigating the system 1	0	06/03/2009 11:53	06/03/2009 11:53
Navigating Vistas of Negativity and Positivity 1	0	02/05/2007 13:55	14/06/2007 12:05
Never enough 1	0	30/05/2007 13:50	14/06/2007 11:44
Noticing little things 1	0	23/05/2007 13:58	11/07/2007 12:21
Noticing little things 2	0	11/07/2007 10:38	11/07/2007 14:42
Nuturative protecting 1	0	06/03/2009 11:53	06/03/2009 11:54
Nuturative protecting 2	0	06/03/2009 11:54	06/03/2009 11:54
Nurturing self and other 1	0	06/03/2009 11:58	06/03/2009 11:59
Nurturing self and other 2	0	06/03/2009 11:54	06/03/2009 11:58
Nurturing self and other 3	0	06/03/2009 11:59	06/03/2009 11:59
NY1 GT SeminarOct 07	0	06/11/2007 13:50	06/11/2007 13:52
NY2 GT Seminar Oct 07	0	06/11/2007 13:51	06/11/2007 13:51
NY3 GT Seminar Oct 07	0	06/11/2007 13:52	06/11/2007 13:52
NY4 GT Seminar Oct 07	0	06/11/2007 13:52	06/11/2007 13:53
NY5 GT Seminar Oct 07	0	06/11/2007 13:53	06/11/2007 13:54
One sided talking 1	0	14/06/2007 10:51	14/06/2007 11:08
Ontological dissonance	0	06/03/2009 11:34	06/03/2009 11:34
Overview	0	06/03/2009 12:01	06/03/2009 12:01
Perceiving difference 1	0	14/06/2007 11:58	14/06/2007 11:59
Perceiving difference 2	0	14/06/2007 13:36	15/06/2007 12:19
Perceiving difference 3	0	14/06/2007 13:49	14/06/2007 14:01
Perceiving difference 4	0	15/06/2007 12:18	15/06/2007 12:49
Perceiving difference 5	0	26/06/2007 14:35	26/06/2007 14:39

Appendix 22 Conference Presentations [62]

Nolan, L., McCarron, M., McCallion, P. and Murphy-Lawless, J. (2006) Presentation of the findings of Perceptions of Stigma in Dementia: an Exploratory Study. Presented at: The Right to be Heard. The Alzheimer Society of Ireland, Annual National Conference 2006, Sligo Park Hotel, 18th November.

Nolan, L., McCarron, M., McCallion, P. and Lawless, J. (2007) Exploring Stigma in Dementia in an Irish Context. Presented at: Citizenship: Responding to the Challenge of Dementia. The Dementia Services Development Centre 1st International Conference, University of Stirling, Scotland, 3rd-4th April.

McCarron, M., Nolan, L., McCallion, P. and Murphy-Lawless, J. (2007) "Loss of Place" Understanding Dementia-related Stigma from an Irish Perspective. Presented at: The Sound of Silence, 17th Conference of Alzheimer Europe, Estoril, Portugal, 9th-12th May.

Nolan, L., McCarron, M., McCallion, P. and Muprhy-Lawless, J. (2007) 'Stigma in Dementia' - reality or myth, supportive or non-supportive? Poster presentation at: The Annual Scientific Meeting of the Irish Gerontological Society, 21st-22nd September.

Nolan, L. (2008) Conceptualising Ethical Research Practice in Terms of Supportive Ethical Pillars – an Explication of One Researcher's Experience. Presented at: 27th International Nursing and Midwifery Research Conference, Royal College of Surgeons in Ireland, February 20th-21st.

Nolan, L. (2008) Linking 'Citizenship' and the Experiences of Lay/Informal Carers. Presented at: Embracing the Challenge: Citizenship and Dementia, The Dementia Services Development Centre Northern Ireland, Stormont Hotel, Belfast, 6th-8th May.

Nolan, L. (2008) Promoting Citizenship in Dementia Research Practice. Poster presentation at: Embracing the Challenge: Citizenship and Dementia, Dementia Services Development Centre Northern Ireland, Stormont Hotel, Belfast, 6th-8th May.

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[62] These presentations are in chronological date order in line with the ongoing theoretical development.

Daly, L. (2008) Sensitive subjects and vulnerable participants: managing the qualitative data collection process in dementia research. Presented at: The Annual Scientific Meeting of the Irish Gerontological Society. Kilkenny, 3rd-4th October.

Daly, L., McCarron, M., Higgins, A. and McCallion, P. (2009) Conceptualising Family Care: Using classic grounded theory to understand the process of informal dementia care. Poster presentation at: Facing the Future, The Dementia Services Development Center's 4th International Conference, York Race Course, York, United Kingdom, 14th-16th September.