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Use of day centers for respite by help-seeking caregivers of individuals with dementia

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Keywords

day, centers, dementia, individuals, caregivers, seeking, help, respite

Disciplines

Arts and Humanities | Life Sciences | Medicine and Health Sciences | Social and Behavioral Sciences

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Use of day centers for respite by help-seeking caregivers of individuals with dementia

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The beliefs that help-seeking caregivers of people with dementia hold regarding the use of day centers for respite

Abstract

Addressing the under utilisation of respite services in caregivers of people with dementia is an important task to improve social support amongst this vulnerable group. This paper utilises theory to conceptualise the behavioural, normative and control beliefs that caregivers of people with dementia associate with the use of out of home day centers for respite. Interviews and focus groups with 36 caregivers were undertaken to explore the beliefs of both users and non-users of services. Whilst service users held positive beliefs, non - users perceived negative outcomes for the care recipient with dementia, or faced barriers associated with their behavioural or physical needs. To address negative perceptions, nurses may need to promote the benefits of day centers for both caregiver and care recipient. However, improvements in program activities and environments, staff development and caregiver support are also required to address negative beliefs and meet the needs of those currently not accessing care.

Keywords: Dementia, community care, respite, day centers, beliefs

Background

Since the late 1980s, domiciliary, day and respite services have been at the forefront of government community care strategies to support the elderly to remain living in their own homes for as long as possible (McDonald, 2006). One group with particularly significant care needs are those with dementia and their caregivers. Having dementia is associated with increasing age and those with dementia suffer profound cognitive and functional disability (Ferri, et al., 2005). As such, the majority of those with dementia who continue to live in the community do so only with the support of an informal carer, usually a family member such as their spouse or adult child (Australian Institute of Health & Welfare [AIHW], 2006; Personal Social Services Research Unity [PSSRU], 2007).

Formal services can support family caregivers in the challenging role of caring for someone who has dementia. The provision of 'respite' [the temporary relief of the caregiver through the provision of substitute care] (Petty, 1990) is one support strategy that is both highly desired by caregivers (Australian Bureau of Statistics [ABS], 2004) and associated with increased caring longevity (Eagar, et al., 2007; Parker, Mills & Abbey, 2008). As both community and government preferences are for the non-institutional care of the ageing population (Department of Health & Ageing [DOHA], 2006; Runge, Gilham & Peut, 2009), this makes the effective provision of respite services to this vulnerable group of critical importance. In this, nurses play a critical role in facilitating assessment, referral and respite service provision to caregivers of people with dementia. This may include a role in direct client care and, for service managers, a responsibility for the promotion and development services.

Respite services can be delivered in the home, in an out-of- home day center or as short-term care over days or weeks in a residential care facility (AIHW, 2006; Gottlieb & Johnson, 2000; Montgomery, 2007). Though not extensive, the research regarding respite

service use behaviours in caregivers of people with dementia spans two decades. Although caregivers of people with dementia are more likely to utilise respite care than caregivers of people with other disabilities (AIHW, 2009; Schofield, Murphy, Herrman, Bloch & Singh, 1998), the overall proportion who use available programs still tends to be low (Cox, 1997; Lawton, Brody & Saperstein, 1989; Montgomery & Borgatta, 1989). This includes relatively low use of day center programs (Biegel, Bass, Schulz & Morycz, 1993; Brody, Saperstein & Lawton, 1989; Gaugler, Kane, Kane, Clay & Newcomer, 2003; Gaugler, Kane, Kane & Newcomer, 2005). Caregivers of people with dementia who do access day center programs tend to do so late in the caring trajectory (Cox, 1997; Kosloski & Montgomery, 1993). As such, they are usually already providing substantial direct care to their relative (Cox, 1997; Zarit, Stephens, Townsend, Greene & Leitsch, 1999) and experiencing considerable stress (Kosloski & Montgomery, 1993; Zarit, et al., 1999). In addition, of those that do enroll in day programs, they only utilise programs at very low intensities (Lawton, et al., 1989) and attrition rates are also high, with discontinuation of program use often occurring within months of commencement (Cox, 1997; Zarit, et al., 1999).

Evaluations assessing the impacts of center based day respite programs reinforce that the timing and utilisation of these services by caregivers has been 'too little, too late' (Gottlieb & Johnson, 2000). However, despite low use, many caregivers of people with dementia report an increased need for respite in general (Armstrong, 2000; Schofield, et al., 1998), and specifically for day care (Armstrong, 2000). To address this need, nurses and other health professionals charged with the responsibility of facilitating access and delivering day care services would benefit from a more comprehensive understanding of factors that make service use difficult or unattractive for some caregivers.

There is limited research regarding factors which may influence the use of day centers by caregivers of people with dementia (Phillipson & Jones, 2009). Not knowing where to find

services can be a significant barrier to the use of day services by caregivers of people with dementia (Montoro-Rodriguez, Kosloski & Montgomery, 2003). Likewise the nature of the caregiver relationship appears significant, especially to spousal caregivers, who are less likely to initiate (Levesque, Cossette, Potvin & Benigeri, 2000) and sustain day center use (Zarit, et al., 1999) than caregivers in non-spousal relationships. Brief rather than sustained use of day centers has been associated with caregivers having had a low level of formal education, as well as with caring for a male care recipient or for someone with high functional impairment (Zarit, et al., 1999). Caregivers who report a high level of disturbance in relation to the functional deficits of the care recipient are also less likely to use day centers (Levesque, et al., 2000).

The beliefs and attitudes that caregivers hold about the use of different types of respite services can also influence their service use behaviours. In fact, studies which have focused specifically on consumer attitudes to respite have found these to be more powerful in predicting respite service use than either caregiver or care recipient need (Kosloski & Montgomery, 1993). Attitudes that influence caregivers' use of different types of respite services include perceived utility (Kosloski & Montgomery, 1993; Montoro-Rodriguez, et al., 2003) and quality (Clark, Bond, Nankivell & Jarrad, 1995; Kosloski & Montgomery, 1993). Trust in services and perceived convenience are also important (Pedlar & Biegel, 1999). However, little is known about the attitudes and beliefs of caregivers of people with dementia regarding the use of day centers specifically, rather than just 'respite' in general (Phillipson & Jones, 2009).

To design effective interventions which promote day center use, behavioural theory and intervention models suggest that the targeting of *specific beliefs* that contribute to overall service use *attitudes* may be an effective approach to promoting behaviour change (Fishbein & Ajzen, 1975; Ajzen, 1991; Fishbein, 2008). In this case, interventions designed to target

the specific beliefs that inform caregivers' perceptions of day center utility, quality and convenience are likely to be more effective, than those that target attitudes to respite use in general.

To inform nursing practice, this study applied the Theory of Reasoned Action [TRA] (Fishbein & Ajzen, 1975) and the Theory of Planned Behaviour [TPB] (Ajzen, 1991) to explore and describe the behavioural, normative and control beliefs of caregivers of people with dementia in relation to their use of out of home day centers. This paper specifically focuses on identifying beliefs informing day center use, and whether these beliefs differ for service users and non-users.

Methods

A qualitative approach was taken in this research. The primary objective was to illuminate and understand day center use from the perspective of help-seeking caregivers. Recruitment was via letter through an agency coordinating the local branch of a National Respite Telephone Helpline. This helpline is promoted by the federal government in Australia as the gateway to care and support services for caregivers. As such, the study was focused on the perspectives of those caregivers who had actively enquired about access to respite or other support services.

Caregivers were subsequently followed up by telephone. Data were collected utilising focus groups, individual interviews and interviews dyads (two participants and an interviewer) (Krueger & Casey, 2000 ; Morgan, 1988; Ritchie, 2001) with a purposeful sample (Patton, 2002) of help seeking caregivers of people with dementia. Caregivers were provided with choice and flexibility in regards to their participation in either an interview or a group discussion to improve the response rate by accommodating preferences (Daly, Kellehear & Gliksman, 1997). Utilising different data collection methods in combination

also enabled the collection of rich data from multiple perspectives (Krueger, 1994 ; Morgan, 1988; Ritchie, 2001).

A semi-structured discussion guide was utilised to elicit views from caregivers who were asked to identify whether, how and under what circumstances they currently used out of home day centers to provide them with a break or respite. To explore behavioural beliefs, caregivers were asked to describe any outcomes that had arisen as a result of day center use or, for non service users, outcomes that they anticipated could arise if they did use services. To explore control beliefs, caregivers were asked what factors they felt made day center use easy or difficult. Normative beliefs for service use were explored by asking caregivers to describe any people, groups or organisations that supported or discouraged their use of day centers. Questions were open-ended, and probes and follow-up questions were utilised to encourage caregivers to think about and discuss each of the factors raised.

All discussions were audio recorded and professionally transcribed. Consistent with content analysis (Berg, 1989) transcripts were initially categorised and coded to identify behavioural and normative beliefs from the TRA (Fishbein & Ajzen, 1975) and control beliefs from the TPB (Ajzen, 1991). Initial coding by the first author involved segments of similarly coded text being grouped for re-reading and analysis. Resultant themes were then reviewed by the second author, and refined until agreement was reached between both coders (Crabtree & Miller, 1992).

To ensure face validity and credibility of the thematic analysis, member checks (Lincoln & Guba, 1985) were conducted via presentation of the study results at community forums. Research participants and other interested community members were invited to attend forums and provide feedback on the analysis and study results. Participants who attended forums confirmed that results were consistent with their interviews and their

experience. The study protocol and materials were reviewed and approved by the University Human Research Ethics Committee.

Results

Five focus groups, two dyads and ten interviews were held with a total of 36 primary caregivers in a metropolitan center about one hour south of Sydney (NSW, Australia). The demographic characteristics of study participants and those for whom they provided care are presented in Tables 1 and 2. The sample represented both male and female caregivers and care recipients, as well as different types of caregiver relationships (e.g. spousal and non-spousal caregivers). There were also three caregivers of people with younger onset dementia, and three caregivers who were born in non-English speaking countries of origin.

As a group, the majority of carers (n=29) received support from formal community services and 21 indicated receiving support from their informal network (i.e. family or friends).

Care recipients had been diagnosed variety of dementia types. Average time since diagnosis was five years (ranging from two to 13 years). In regards to functional status, most required a lot of assistance (n=15), or at least a little assistance (n=17) to perform their activities of daily living, seven had a problem with wandering, and 16 reportedly exhibited behaviours such as yelling, swearing or other signs of restlessness.

The Beliefs of Caregivers who Utilise Day Care Centers

A summary of the beliefs that service using caregivers hold in relation to day center use are presented in Table 3. The behavioural beliefs that users associated with day center attendance were linked to positive outcomes for the person with dementia. Perceived beneficial outcomes for the care recipient included gains from social interaction or mental stimulation beyond the home. Some caregivers perceived day centers provided something

additional to what they themselves were able to offer. In addition, for working caregivers, day care centers provided longer periods of supervision than was available in the home. Outcomes associated with day center utilisation by caregivers who accessed services were perceived as enhancing or improving the quality of life of the person with dementia.

> *'Getting out on the bus was great...and all the activities. It was something I couldn't give him....they cooked, had film nights...social nights and I thought well we don't do that at home.' Caregiver, Interview 1*
>
> '*With me working I started to worry about mum at home all day, even with the carers popping in. She needed something, some more stimulation...some kind of group that she could tap into away from us' Caregiver, Interview 4*

Day center use was also associated with beliefs about dementia. These included beliefs that people with dementia benefited from being engaged in positive occupation that enhanced their personhood or sense of self. Caregivers perceived day center environments as beneficial when the person with dementia was recognised as having skills, abilities and a capacity to engage in purposeful activities. For some caregivers, this experience of quality time for the person with dementia also had outcomes for the behaviours of the person beyond the timeframe of their physical attendance at the center.

> *'When he first came they asked him about his hobbies and I said he plays the piano, he learnt when he was young. And she said 'you can entertain everyone' and she put him at ease. At home he hardly ever touches it but he comes home and says he played and they were all dancing. They make the patient feel important and give them a positive role to play. He loved going because it made him feel worthwhile.' Caregiver Group 2*

'When she got over the initial reluctance ...she loved going and even if she didn't remember where she was going she'd come home with this emotional memory. She was more settled for the whole week when she was having outings and day care...So it did her good even if she couldn't remember where she'd been. A really positive experience...'.Caregiver, Group 4

Behavioural beliefs associated with the use of day centers were also influenced by the caregivers' perceived need for respite. The constancy of caregiving responsibilities was highlighted by the appreciation of the time day center use allowed them to engage freely in everyday activities. Caregivers valued the time to attend to social and practical needs, and the opportunity to attend to the needs of other family members or friends, which was sometimes difficult due to the constant demands of caring for their family member with dementia.

'I feel it frees me up, even to talk on the phone or read, or do a crossword. When he's there you can't do any of that. If I'm on the phone more than 2 or 3 minutes he's agitated and thumping round wanting my attention. Just having him out of the house so I'm free to read, or go and get my hair cut, that's a big thing.' Caregiver, Group 2

'And it's a good time to catch up with friends and relax and talk to someone else, it makes such a difference them being in day care...' Caregiver, Group 3

'Day care helps you to do things, if you had to go to the doctor, or another appointment, or just to have a day to yourself.' Caregiver, Dyad 1

'[*Before she started attending day care]..... I found I was giving so much time to her I wasn't giving my other family members any time and I had no time for myself.' Caregiver, Group 2*

The utility of day care for one caregiver had also been enhanced by the opportunity to observe the way that formal paid care staff managed her husband's behaviours. This usually occurred during the short time that the paid carer entered the home environment to assist her

husband on to the bus. This did not appear to be an outcome that she had anticipated would arise from day care use. As such, whilst it is unlikely to have contributed to decisions regarding initial use, it may have been a beneficial outcome that helped to sustain use. It is also evident from her response that there was potential for this benefit to be further enhanced through her being enabled to visit the day center her husband attended.

> *'She is just marvellous you know [the paid carer]. Her excellent manner, skills, expertise and I try and notice what they do with him, you know...I really like their attitude and I find myself trying to copy them...when I am having problems...thinking now how would they approach this? Unfortunately I am not in a position to do observe their behaviours at any length. There is no opportunity for [family] carers to attend the center... but I often think I would like to.' Caregiver, Interview 3*

For some, the use of day care centers had been associated with negative personal attributes such as failing or not coping. As such, the ability to transition from non-use to service use had required them to overcome these beliefs. This occurred as a result of a realisation that service use had become a necessity if they were going to continue in their caregiving role. Acceptance of the need to use day care services had therefore come as a means to extending caregiving longevity. This process for some caregivers had been facilitated by the support of nursing care staff from the day centers concerned.

> *'I thought I'd manage better than this, you know....I guess you could use the word, failure if you wanted to... but I couldn't allow that thought to stay with me because I knew I had to survive, I had to have help.' Caregiver, Interview 5*
>
> *'I initially found myself thinking, I'm the only person… the only one who can't do this, who can't get it right. But then, I began to realise that actually I was normal...they [the day center staff] helped me realise that it was normal to need a*

break...and after I accepted their offer...I could finally see that it works.' Caregiver, Interview 6

For others, reflecting on the outcomes associated with getting a break came after the fact. Rather than anticipating them before using respite, it was an afterthought that maybe if they hadn't accessed the service, sustaining their caring role may have been more difficult.

'If I hadn't had [day care], I don't think I could have looked after him as long as I did' Caregiver, Interview 7

For service users, control factors that made the use of day centers easier were receiving assistance to find a center that met the needs of the care recipient, as well the provision of assistance with transport.

'Having someone [a community worker] to help me sort through what was the right and wrong place to send him, given his needs…that made a real difference….as did the fact that they were able to provide transport to the center and home again…without that it all would have been too hard' Caregiver, Group 3

The Beliefs of Caregivers who do not Utilise Day Care Centers

Whilst many caregivers may perceive utility in the use of day centers to provide themselves with a break, they may not also have perceived benefit in service use for the care recipient. For many caregivers who did not use day centers, potential day center use was not associated with the improved quality of life of the person with dementia, and this was a significant barrier to service use.

'They just sit there and vegetate as the staff go about their business. And I said there's no way I would have that. A person with dementia still has a mind. They still need to do things so I keep him as active as possible.' Caregiver, Group 2

The importance of the experience of the care recipient was highlighted by many caregivers who saw the needs of the person with dementia as paramount to their own need for a break.

'Sure, I need a break...but I would only want her to go if she was happy… she would have to get something from it too.' Caregiver, Group 7

Control factors or beliefs also influence the non-use of day centers by some caregivers who reported a perceived need for respite, but had been unable to successfully negotiate attendance with the care recipient. Whilst conflict was tolerated by some caregivers who persisted with day center use, for others an inability or unwillingness to overcome care recipient reluctance resulted in not utilising available services. Some caregivers of male care recipients felt that the day center setting was not appropriate for older males who were, in their minds, less predisposed to participation in group social settings outside the home. This could be informed by normative beliefs or stereotypes concerning 'what older men do'. This belief also appeared to be informed by the previous behaviours and preferences of the older males concerned.

"He isn't a great one for socialising. He's never been one for small talk…no interest in just chatter…so day centers wouldn't benefit him' Caregiver, Group 4

Caregivers of people with younger onset dementia had their non-use of day care reinforced by the views of staff that current services were not really appropriate for them because of their age. This view may be informed by normative beliefs that it is not appropriate to care for younger and older people in the same social setting or environment.

'He went along once to the dementia day care...but when I picked him up they told me he shouldn't come back....that he didn't belong there. And they were right...he was too young...he just didn't fit in'. Caregiver, Group 6

'Yes, they did mentioned a day care center but because of his age we all agreed that he's really too young to mix with these people. Most of them are older, you know. They're retired, seventies, eighties, you know what I mean?' Caregiver Interview, 2

The experience of some caregivers had also informed their beliefs that day centers were unable able to meet the specific needs of the person for whom they cared. Examples from the discussions included physical problems, such as hearing or mobility deficits, as well as behavioural problems.

'I don't know how to put this but the only attempt that was made to go… after only a short time they rang us. And my daughter in law had to go and pick her up. She became a problem…they couldn't manage her behaviour… it certainly didn't work.' Caregiver, Group 7

'Mum was not able to get up on to the bus...they had to be able to take three steps up... and I thought surely a place like this that is catering for older people should have some kind of ramp or facility for the physically frail?" Caregiver, Interview 4

'The group setting really didn't suit her… she suffers from acute hearing problems so she couldn't cope with the noise…can't keep up with the conversation and so I judged rightly or wrongly that she couldn't cope with that type of respite…even though it could have been great for her to have some other stimulation… and for me to get some relief.' Caregiver, Interview 7

Discussion

The use of behavioural theory in this study was useful to highlight the numerous factors that nurses may need to address to target underutilisation of day center respite services by caregivers of people with dementia. Behavioural beliefs highlight that service users perceive utility in day centers for both themselves and the person with dementia for whom

they provide care. Whilst users and non-users both may perceive that day care can provide them with a needed break, those that go on to utilise care also perceive positive outcomes for the care recipient. These include opportunities for social participation and mental stimulation. This is in contrast to non-users who either don't perceive the same benefits for the care recipient, or who may anticipate negative outcomes such as conflict in the caring relationship or deterioration in the care recipient's affective state.

These results have important implications for nurses involved in the promotion and referral of caregivers and people with dementia to day centers. Firstly, to encourage service use, nurses may need to re-position the way centers are promoted, emphasising potential benefits for both caregivers *and* care recipients. This would be in contrast to the way that services are currently promoted in community care, where the primary emphasis is on meeting the needs of the caregiver for a break (e.g. Carlson, Abbey et al., 2009).

Describing the normative beliefs of caregivers is useful to highlight that caregivers who use day care tend to have accepted their own need for a break as legitimate. This was linked to outcome beliefs (e.g. that day care was useful to extend caring longevity) and also, consistent with Cottrell's findings (1996), to attend to social and practical needs. As such, service use for these caregivers was associated with positive caregiving norms. Non-users however, may position service use with failure or not-coping. This is particularly the case when the care recipient refuses or is reluctant to attend. This suggests that nurses working with caregivers of people with dementia may also need to promote use as normative to extended caregiver longevity, rather than being associated with failure. This is an outcome desired outcome by both caregiver and care recipient. The capacity for nurses to influence caregiver attitudes to service use should not be underestimated, with evidence from this study that service providers can act as important social referents, able to positively influence caregiver beliefs that day care use is valid and acceptable.

However, whilst it may be possible to address some negative beliefs through positive promotional strategies, control beliefs highlight that negative outcomes have been associated with programs being unable to meet the physical and/or behavioural needs of some care recipients. Supporting those who care for people with complex behavioural and physical needs may come via improvement in nursing assessment and referral pathways. However, it is likely that improvements to care environments and specialist staff training may also be required to deal with the complex behavioural and psychological symptoms that can be associated with the experience of dementia.

This study suggests that caregivers' perceptions of utility and quality are enhanced when nurses in day care environments possess specialist dementia skills, and the capacity to provide education and support for family caregivers. This extends the conceptualisation of service provision in the day care environment beyond the provision of substitute care, to being inclusive broader caregiver needs.

Advocacy for lower nurse caseloads may be required to acknowledge the time taken to comprehensively assess and facilitate the service use of people, such as those with dementia, who have particularly complex needs. Nurses working in day respite centers and in the community may also need informational support to enable them to refer to other local services as it is likely caregiver caregivers may require multiple supports (Brodaty, Thomson et al., 2005). In the Australian context, aged care and dementia services are provided by a complex array of government and non-government providers (Brennan, 2010), and can be very difficult for caregivers and health professionals alike to navigate. Positive control factors raised by caregivers emphasise the importance of assistance to navigate the system and the need to consider other practical supports that facilitate service use such as transport.

Control and normative beliefs also highlight that the needs of specific target groups may not currently be well met by existing day center programs (e.g. older males, people with

younger onset dementia and those with the behavioural and psychological symptoms). These results point to a need for the development of programs (and referral pathways) tailored specifically to meet the needs ofthese particular subgroups. Whilst some existing pathways articulate the importance of tailoring services to meet caregiver and care recipient needs (Carlson, Abbey, Palk & Wise, 2009), they do not consistently acknowledge the resource constraints that limit care practices in many local areas.

Arguably, care in the community has been limited due to the limited guidance provided to nurses and other health professionals on effective ways to co-ordinate and manage the responsibilities for the promotion, assessment, referral and delivery of respite services. Partly addressing this gap, this paper highlights the utility of consumer research, informed by behavioural theory, to assist in building an evidence base for gerontological nurses to increase the use of day respite services. The study, however, was not inclusive of the perspectives of those caregiver who had not yet attempted to access respite services, who may hold additional beliefs to those highlighted in this study, and should be investigated in future research.

It is also likely, that the system itself may require additional funding and resources to address the educational, case management and support needs that caregivers have raised. As such, nurses could consider ways to collect data at a local level to build the evidence base required for broader advocacy strategies (e.g. lobbying) for the additional resources that may also be required from government or the private sector to better meet caregiver and care recipient needs.

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Table 1: Demographic characteristics of caregiver participants

	Total	Focus groups	Interviews	Dyads
Caregivers	n=36	n=22	n=10	n=4
Gender	Male (10) ; Female (26)	Male (6) ; Female (16)	Male (3) ; Female (7)	Male (1) ; Female (3)
Age	Average = 71 years Range = 43 to 87 years			
Relationship	Spousal (25); Non-spousal (11)	Spousal (17); Non-spousal (5)	Spousal (6); Non-spousal (4)	Spousal (2); Non-spousal (2)
Co-residency (Yes)	Yes = 27; No = 9	Yes= 16 ; No= 6	Yes = 9; No = 1	Yes = 2; No= 2
Country of Origin (Non-English Speaking)	Yes = 3; No = 33	Malta (1)	Germany (1)	Finland (1)
Education	Primary (5); Secondary (16); Technical (5); University (8)	Primary (4); Secondary (10); Technical (1); University (5)	Primary (1) ; Secondary (5); Technical (2); University (2)	Secondary (1); Technical (2); University (1)
Informal Support from family/friends (yes)	Yes (21); No (15)	Yes (13); No (9)	Yes (5); No (5)	Yes (3); No (1)
Use of formal services for support	Yes (29); No (7)	Yes (16); No (6)	Yes (10); No (0)	Yes (3); No (1)

Table 2: Demographic characteristics of the people with dementia for whom the caregivers provided care

Care Recipients	n=36	n=22	n=10	n=4
Age	Average = 76 years Range 55 to 88 years			
Gender	Male (23) ; Female (13)	Male (14) ; Female (8)	Male (7) ; Female (3)	Male (2) ; Female (2)
Country of Origin (Non-English Speaking)	Yes = 3; No = 33	Malta (1)	Germany (1)	Finland (1)
Diagnosis	Alzheimer's disease (15), vascular dementia (6), Lewy Body Disease (3), Fronto-Temporal Lobe dementia (2) and other (2); unknown (6); no diagnosis (2)	Alzheimer's disease (7), vascular dementia (4), Lewy Body Disease (3), Fronto-Temporal Lobe dementia (2) and other (2); unknown (2); no diagnosis (2)	Alzheimer's disease (6), vascular dementia (2); unknown (2);	Alzheimer's disease (2), unknown (2)
Time since diagnosis	Average = 5 years Range = 2 to 13 years			
Assist with ADLS	A lot of assistance (15), a little assistance (17), no assist (4)	A lot of assistance (11), a little assistance (9), no assist (2)	A lot of assistance (4), a little assistance (5), no assist (1)	A lot of assistance (0), a little assistance (3), no assist (1)
Behaviours	Wandering (7) Other behaviours (16) e.g. yelling, swearing or other	Wandering (5); other (10)	Wandering (2); other (4)	Other (2)

	signs of restlessness			

Table 3: Beliefs associated with the use of day care centres by caregivers of people with dementia

Types of beliefs	Caregiver Beliefs
Dementia beliefs	People with dementia benefit from being in a different social environment beyond the home
	People with dementia benefit from social stimulation
	People with dementia benefit from mental stimulation
	Care for people with dementia should be based on a personal knowledge of the person
Normative Beliefs & Motivations	Carers need time to attend to their own social needs e.g. friends, family, hobbies etc
	Carers need time to attend to other practical needs e.g. shopping, bill paying etc
	Carers need a 'break' from their caring responsibilities
	Carers who send the person they care for to a day centre are 'not coping' with their responsibilities
Behavioural Beliefs & Outcome Evaluations	Provides time for caregivers to attend to social and or practical needs
	Provides positive social benefits for the care recipient with dementia
	Provides positive emotional benefits for the care

	recipient with dementia
	Provides positive behavioural outcomes for the care recipient with dementia
	Provides extra activities for the person with dementia that the primary caregiver can't provide
	Increase's a carers ability to continue in their caring role for longer
	Provides learning opportunities for informal carers to gain additional skills and knowledge
Control Beliefs	Accessing day care is easier if someone helps you find the right center
	The provision of transport makes the use of day centers easier

Table 4: Beliefs and other factors associated with the non-use of day care centres by caregivers of people with dementia

Types of beliefs	Caregiver Beliefs
Dementia beliefs	People with dementia may be unsettled by being in a different physical or social environment beyond the home
Normative Beliefs & Motivations	Carers who send the person they care for to a day centre are 'not coping' with their responsibilities
	Day centres are not appropriate social settings for older male care recipients
	It is not appropriate to care for younger and older people with dementia in the same social environment
Behavioural Beliefs & Outcome Evaluations	Provides positive no perceived benefits for the care recipient with dementia
Control Beliefs	The person I care for refuses to attend a day centre
	Day centres cannot meet the functional needs of the person I care for
	Day centres cannot meet the behavioural needs of the person I care for