

EXCLUDED VOICES IN DEMENTIA CARE

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A Thesis

Submitted to the School of Graduate Studies

In Partial Fulfillment of the Requirements

For the degree

Master of Social Work

McMaster University

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MASTER OF SOCIAL WORK
(2008)

McMaster University
Hamilton, Ontario

TITLE: Excluded voices in dementia care

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NUMBER OF PAGES: vi, 41

ABSTRACT

The principles of person centred care have been widely espoused in dementia care. However, the language and conceptualization of person centred care is primarily articulated ‘top down’: from the vantage point of health and social care professionals, academics and policy makers. The perspectives of family caregivers have not been well explored – a striking omission since it is they who are most likely to have closest knowledge of the ‘persons’ with dementia. The purpose of this study was to learn from family caregivers of people with dementia the meaning of “person-centred care” and thus, to generate a ‘bottom up’ view of its conceptualization that can contribute to informing and improving service delivery in dementia care.

A small qualitative study of family caregivers was conducted in Ontario using personal interviews to explore their accounts of the degree to which the care their relatives received was knowing or unknowing, i.e. knowledgeable about the ‘persons’ supposedly at the centre of person-centred care. Analysis of their accounts revealed some key themes: caregivers’ attention to establishing their positions as ‘knowers’, their efforts to enable knowing care of their relatives, and their responses when they witnessed unknowing care. The study also illuminated the consequences of unknowing care for individuals with dementia and their family caregivers. Findings revealed that family caregivers perceived person-centred care as closely linked to a dynamic process in relationship building between service providers, family caregivers and persons with dementia. Barriers to the implementation of person centred care were discussed and implications for social work practice and advocacy considered.

ACKNOWLEDGEMENTS

This study would not have been possible without the participants who so willingly and generously shared their stories and experiences. They are an inspiration to me for their courage and resiliency. Thank you all.

There were times where self-doubt crept in as I despaired over the study. Many thanks to my thesis supervisor, Jane Aronson, for her incredible ability to keep me grounded throughout the study, for her enthusiasm, encouragement and words of wisdom. Her patience in the last few weeks of the study is truly appreciated. The cups of tea helped.

I would also like to thank the various service providers for putting me in touch with the participants. To preserve anonymity, they will not be named. Many thanks also to my adopted families and friends who had been so supportive, kind and generous in keeping me supplied with food.

To my family members in different parts of the world who have been very patient, while I ‘holed up’ in the last two years completing my studies, the reunion is happening very soon. It has been too long.

Lastly, to my sister who passed away in the midst of my studies. She had always encouraged and supported me to pursue more education, to gain more knowledge and to use them wisely for the greater good. Thank you sis.

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INTRODUCTION

Dementia is seen as an impending epidemic that will sweep over the health care system as the population ages, a phenomenon that Canada will be facing in the next 10-15 years as the baby boomers enter their senior years. In 2007, 450,000 Canadians had dementia, with the number estimated to increase to 750,000 by the year 2031 (Alzheimer Society Canada, 2008). It is approximated that 1 in 13 Canadians over the age of 65 and 1 in 3 over the age of 85 has dementia (ibid). Globally, the current estimate is that there are 24 million people with dementia, with the number expected to increase to 81 million by the year 2040 (Alzheimer's Disease International, 2005). What these statistics are saying is that as the population ages, the number of people with dementia will increase, a phenomenon that will be facing Canada as the seniors' population is rising. In 2006, seniors comprised 13% of Canada's population, compared with 10% in 1981 and only 5% in 1921. By 2056, the share of the population aged 65 and older may reach 27% (Statistics Canada, 2007). It is expected that the cost to health and social care systems will be significant as the number of people with dementia rises. In the United States, the annual direct and indirect cost of caring for people with dementia is estimated at US\$100 billion (Alzheimer's Disease International, 2005).

The statistics provide a challenging picture about the future of dementia care at the local and global level. A sobering aspect of the challenge is the association of old age with dementia and the double jeopardy that comes with being old and having dementia. Living in a society that cherishes the 'young and the bright' and holds in high regard those who are economically productive, an image of an elder who is confused arouses human emotions that range from pity, shame or fear. The media portrayal of people with dementia also plays a significant role in how they are viewed by the public. In 2005, the media reported that two residents in a long term care home in Toronto were killed by another resident who had dementia. In June 2008, the Canadian Broadcasting Corporation (CBC) investigative news series on long term care homes in Ontario (CBC, 2008) provided more stories of residents being attacked by co-residents who have dementia. These media stories conveyed that people with dementia are violent and to be feared as they are 'out of control'. The media portrayal and the "hypercognitive" (Post, 2000) culture we live in, a culture that values cognitive abilities, contributes to dementia being cited as the second most feared disease for Canadians as they age (Alzheimer Society Canada, 2008). The fear of losing control, of not remembering one's identity, family members or friends, is a phenomenon that is akin to death for some people.

As a social worker in a local chronic care hospital, I see the impact of dementia on the lives of people on a daily basis. I see persons with dementia whose conditions are such that they can no longer communicate their identity and wishes. As such, involved family members are crucial as their representatives, to be the voice to communicate their values, needs and preferences. There were many instances where I encountered amazing family members whose lives had been disrupted by their relative's dementia and yet their commitments to them were unwavering. Their willingness and generosity to share their

experiences and stories highlighted their resiliency and dedication to their relative. The stories they shared about their relative revealed rich lives that were often not apparent in the daily tasks of caregiving, either in the community or in institutional settings. I heard poignant stories about care practices that ignored unique characteristics and needs of people with dementia, practices that disregarded the 'personhood' of people with dementia. I have also heard stories from family members about their puzzlement and frustration when their 'expert' knowledge, based on their relationship with their relative with dementia and first-hand caregiving experiences, were discounted. Concerns about impersonal care meted out to people with dementia and impact on the physical, social and emotional wellbeing were consistent themes running through these stories. These stories were illustrations of care practices where the voices of people with dementia and their family members were muted. The focus of care was geared to completion of functional tasks, a model of care delivery that did not allow for the establishment of relationships between service provider and care recipients.

In the literature (Taft, Fazio, Seman and Stansell, 1997, Kitwood, 1997; McCormack, 2003; Brooker, 2004 and 2007), much has been written about 'person centred care'. However, the literature and analysis of care practice is articulated from the vantage point of health and social care professionals, academia and policy makers. The perspective of families of people with dementia, much less those with dementia who are able to communicate and participate in care processes, on 'person centredness' is not well explored, a striking omission since it is they who are most knowledgeable about the person whom this model of care aspires to sustain. The oversight is concerning as when their relatives' illness is such that they can no longer communicate their identities, preferences and wishes, family members play a crucial role in representing them to service providers or institutions and in ensuring that their care is personalized in an informed way. This study is my attempt to address that omission by bringing forth the perspective of families on 'person centred care'. I am interested in finding out how families share the knowledge they have of their relative with dementia to enable service providers to know them and thus provide 'person centred care', and their experiences during the process of knowledge transfer. The goal of the study is to contribute to the prevailing knowledge on person centredness and care practices to people with dementia.

LITERATURE REVIEW

Contested views of people with dementia

Conceptualizations of people with dementia are driven by whether the self is seen as persisting despite the illness. In Western philosophy, there is the assumption that selfhood is tied into cognition (Davis, 2004) and when the cognition starts to fray, it leads to a gradual loss of self. From this perspective, the 'loss of self' in those diagnosed with dementia leads to 'social death': without cognition, the person ceases to exist even though the body continues to live on. The self that defines who we are, the identity that comes from our connections with others, is only supported by our ability to remember who we are and who they are. With the loss of that ability, people with dementia have 'unravelling' and the "unbecoming of self" takes over until there is but emptiness in them (Fontana and Smith, 1989), a shell of who they were before the onset of the disease. This characterization of people with dementia as empty shells, no longer persons, sets the stage for the sterile treatment of people with dementia. In practical terms, the treatment meted out to them is impersonal, based on the rationalization that they do not have any ability to understand, feel or exhibit emotions nor the ability to appreciate human interactions. This line of reasoning for the loss of selfhood accords with the biomedical view of people with dementia as it sees dementia as an "abnormal condition of cognitive impairment, dysfunction, and mental disorder" (Lyman, 1989, p.599). The disease defines the person who has been diagnosed with dementia and it attributes any expression, gesture or behaviour that the person displays as a symptom of the disease (Taft, Fazio, Seman and Stansell, 1997). It paints an image of the person with dementia as being at the mercy of the disease ravaging the body, without hope of a cure and death as its only escape.

Another school of thought suggests that the person is not limited to his/her cognitive function alone, that the self can persist even when cognitive ability ceases to exist. Instead, the construction of self is defined by how others treat and view that person who has dementia (Sabat and Harre, 1992; Kitwood, 1997). From this perspective, being diagnosed with dementia does not mean that the self is lost. Instead, the self remains intact despite the disease and its removal can only happen if the remaining abilities in people with dementia are not supported by others around them (Kitwood, 1997). Further, people with dementia are seen as able to continue to participate in activities that promote their sense of selfhood in spite of cognitive impairment. This belief is supported by studies that showed that people with mild-moderate dementia are able to participate in decision-making and have meaningful conversations (Cotrell and Schulz, 1993; Burgener and Dickerson-Putman, 1999; Feinberg and Whitlatch, 2001; Trigg, Jones and Skevington, 2007). Similarly, Zingmark, Norberg and Sandman (1993) found that people with moderate to severe dementia were able to express feelings of homesickness and at 'homeness'. This body of research literature indicates that people with dementia have intentionality and purpose in their behaviours, gestures and expressions, contrary to the biomedical model that objectifies and sees them in terms of disease rather than people with valid experiences. This person centred view of individuals with dementia not only

subscribes to the notion that people are people despite the loss of memory, but also underscores that they retain their full rights as citizens of society and are entitled to treatment equal to that of those who are more cognitively intact.

The concept of person-centred care in dementia

The person centred view of people with dementia is based on the recognition and the valuing of the 'personhood', which Kitwood (1997) defined "as a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (p. 8). This personhood approach to dementia takes into account not only the neurological changes as a result of the dementia illness but sets it within a social context. As Goldsmith (2002) pointed out, in order to understand a person's dementia, attention must be given to "the complex interaction between their personality, their physical health, their biography or life history, their social psychology (the network of their social relationships) and their neurological impairment" (p. 24). The approach emphasizes that while neuropathological changes exist in a person who is diagnosed with dementia, the social-psychological environment plays a significant role in determining how they are viewed and treated. According to Sabat (2006), "the degree to which persons with dementia can be recognized... depends a great deal on the ways in which they are positioned, understood, and subsequently treated by others" (p. 300). The focus is on the social environment that exists around the person with dementia to create supportive relationships to maintain his/her remaining abilities and personhood (Kitwood, 1997). This paradigm shift in how people with dementia are viewed, from a "focus on the disorder to a focus on the person" (Woods, 1999), stands in direct contrast to the biomedical model of seeing the person through the lens of 'brain pathology' only.

Implementation of person-centredness in dementia care

Since Kitwood first used the term 'person-centred care' in his work with people with dementia, his legacy is seen in the widespread use of that term in dementia care as evidenced by its adoption into the language used by professionals, public and private organizations that provide services to people with dementia. It has become a term assumed to be synonymous with quality care in dementia work. Some variants on the term are used to convey similar meanings, for example, patient-centred or client-centred care. In Ontario, the term 'resident centred care' is used in the Long Term Care Home Act (2007) to reflect care that is individualized to unique needs of residents in long-term care homes.

The principles of person-centredness in dementia care have been translated into different direct care and therapeutic approaches that seek to either reduce the frequency and intensity of behavioural disturbances in people with dementia or enhance social and psychological wellbeing. Kitwood (1997) proposed the use of "dementia care mapping", an observational technique that purported to measure quality of dementia care from the perspective of the person with dementia. It involved using one or two observers, watching

the behaviours of five or six people with dementia over an extended period, usually between three to six hours, to capture activities that support wellbeing or contribute to the ill-being of persons with dementia (Adams, 1996). This technique was found to be beneficial in improving dementia care delivery (Brooker, Foster, Banner, Payne and Jackson, 1998), and in evaluating effectiveness of specific interventions in dementia care settings (Brooker and Duce, 2000). However, the literature on dementia care mapping did not identify seeking input from family caregivers in determining the efficacy of that approach from their perspective, an oversight as involved family caregivers can be invaluable in helping to put into context behaviours demonstrated based on their intimate knowledge of the person with dementia (Berg-Klug and Forbes-Thompson, 2008).

The needs driven, dementia compromised behaviour model is another direct care approach that promotes the practice of person centred care. It maintains that interactions between stable background factors, for example, the person's biography and remaining abilities, and 'proximal' variable factors, such as pain, hunger, physical and social environment, produce needs driven, compromised behaviours and by attending to those unmet needs, disruptive or agitated behaviours will decrease (Richards, Lambert and Beck, 2000). Using this model, Whall et al. (1997) found that by manipulating bathing environment, e.g. playing music in the bathroom, agitated behaviours during care were significantly reduced.

In therapeutic approaches that use person-centred care principles in dementia care, one such approach is the use of 'story telling' as a way to promote understanding and knowledge of the person with dementia. Through the narration of their life stories, family caregivers and people with dementia enable service providers to see them as people who have valid life experiences. In one study by Mills (1997) with people with dementia, it was argued that storytelling did not only provide pleasure to the person with dementia who did the telling, it was also reflected in care being provided in a personal way, grounded in the service providers' knowledge gained from the narration. Similarly, Clarke, Hanson and Ross (2003) interviewed family caregivers, patients and health care professionals and found that the use of biographical approach through storytelling helped service providers to know the 'person behind the disease', facilitated the practice of person centred care and fostered a closer working relationship with family members.

Validation therapy has also been used as a strategy to promote person centredness and it uses the principles of affirmation of feelings, empathy and use of a non-judgemental stance. It was created by Naomi Feil for use with people with dementia as a tool to decrease stress, enhance their dignity and promote their sense of happiness (Feil, 1992). A study done by Deponte and Missan (2007) to determine its effectiveness in reducing behavioural disturbances found some successes in its use. However, the measurement of success was from the viewpoint of professionals based on their observation of participants' behaviours and functional abilities before and after the intervention.

Loss of relationships, isolation and disengagement in everyday activities are issues that confront people with dementia living at home and in institutional settings. It can lead to a decrease in their quality of life and sense of agency. Accordingly, various programmes and services, such as day programmes and respite care, have been designed

to enhance quality of life, provide mental and social stimulation. Research on their effectiveness suggests they have mixed results (Beisecker, Wright, Chrisman and Ashworth, 1996).

The use of meaningful activity as a strategy to enhance personhood and quality of life has been explored in several studies to determine its effectiveness with people with dementia. In one study (Phinney, 2006) that involved family caregivers and people with dementia living in the community, it was found that families were the 'expert' in enabling their relative to continue involvement in activities that promoted their sense of wellbeing and connectedness. In another study (Phinney, Chaudhary and O'Connor, 2006) conducted from the perspective of people with dementia living in the community, the findings indicated that participants were able to express pleasurable emotions, sense of belonging and personal identity and it increased their sense of personal autonomy. The conclusion drawn from this study was that engagement in meaningful activities could improve the quality of life and personhood of people with dementia. Research (Lord and Garner, 1993) on group music therapy in a privately funded long-term care home found that the use of music could improve social interaction and mood. Other strategies and practices used in pursuit of person centred care include reminiscence therapy (Lai, Chi and Kayser-Jones, 2004) and manipulation of the physical and social environment to enhance person centredness (Morgan and Stewart, 1997).

The different direct care practices and therapeutic approaches discussed above are all intuitively logical practices to enhance person centred care. However, they require skilled and sufficient staff to implement and sustain the practices. While they are creative and innovative approaches, implementing those practices in less than ideal or adequately supported conditions is challenging, particularly since they are labour intensive practices.

The 'cult of task and time' in dementia care

The implementation of person centred care is dependent on priority being allocated to the needs of people with dementia and in redressing long standing patterns of inattention characteristic of many health care systems. In Ontario, the lack of adequate funding for long term care homes and increased resident complexity and acuity (Ontario Health Coalition, 2008) constrain the possibilities of practicing the kind of person centred care described above.

The Ontario Health Coalition and other watchful critics and advocates note that the lack of increased funding, despite an increased in resident acuity, means that care providers in these settings were understaffed and overworked. Staff have to work harder and faster and, it is suggested, the culture of care becomes one of survival as long-term care homes juggle to meet the increasing needs of their residents amidst staff shortages. Writing from the United States, Henderson found that the "cult of task and time" ruled the workdays for these workers as they struggled to address the multiple and complex needs of residents, leaving them with little to no time to provide care that is tailored to the needs, preference and values of the residents. Henderson (1995) attributed the task-focused approach in long-term care homes to the biomedical model that governed it. McLean (2007) echoed the same sentiment. What all these meant is that the adoption of

the term 'resident centred care', as used in the Long Term Care Homes Act (2007), becomes rhetoric for care that is not reflective of reality.

Additionally, dementia care is a specialized area of care that needs consistent staff who are adequately trained in dementia approaches. Studies had shown that when person centred care approach was utilized with people with dementia, it decreased their level of agitation and aggression (Sloane et al. 2004) and decreased the use of physical and chemical restraints (Werner, Cohen-Mansfield, Braun and Marx, 1989). However, as long-term care homes attempt to cope with the day-to-day functioning amidst fiscal and staffing challenges, the availability of funding resources to educate and train staff in person centred approaches to care takes a lower priority. As Gladman et al. (2007) argued, person centred care is only achievable if organizational policies and appropriate resources are in place to support its implementation.

The budgetary constraints that face the long term care sector are similarly experienced in the home care sector. In many jurisdictions, in Ontario in particular, they were deepened by market managed competition that was introduced in 1996 in order for the government to rein in expenditures (William, Barnsley, Leggat, Deber and Baranek, 1999). The result was a significant cutback in services to home care clients and an increase in workload demands and unrealistic expectations on home support workers as the drive is for efficiency and effectiveness in delivery of services. The 'cult of task and time' curtails opportunity for relationship development between workers and their clients. Workers did not have time to know the values, needs and preferences of people with dementia, resulting in care provision that was focused on tasks completion instead of relationship building (Aronson and Neysmith, 1996). This is in contrast to studies that had shown that the ability to form a working relationship with care recipients contributed to care providers' sense of job satisfaction (Denton, Zeytinoglu, Davis and Lian, 2002). The low wages and unrealistic demands in home care work also mean that there is a high turnover of home support workers (Piercy, 2000), a challenge for family caregivers and people with dementia as they have to keep adjusting to new workers. Dupuis and Smale (2004) found that lack of consistency of home support workers was one of the primary reasons for the lack of service utilization by some family caregivers of people with dementia living in the community.

The labour intensive and complex practice of person centred care as described above is, in short, very much at odds with the organization and staffing of contemporary long term care, whether in institutions or in the community. The commonplace use of the term or its variants (resident or patient centred care) appears then, to be a delusion, a cover for thin and impersonal care delivery.

The rhetoric in the use of person centred care as a cover for 'thin' care supports the timeliness of this study to enhance our understanding of person centred care from a perspective that is typically unheard and discounted. This commitment to building a 'bottom up' knowledge is akin to comparable efforts to intrude into users' perspective in other service sectors. For example, welfare users are demanding to participate and be included in the politics, philosophy and practices in welfare (Beresford and Croft, 2001). This call for 'user led' rather than 'provider led' practice is also echoed in the disability movement where the voices of people living with disabilities challenge the organizational

and professional discourses that have dominated their landscape (ibid). In dementia care, voices that have been historically excluded are those diagnosed with dementia.

Recognizing this, I would have liked to talk with people with dementia, to get their 'take' on what makes person centred care attentive to them in particular and their experiences of what matters to them most when care is being provided. However, because of institutional ethics' barriers and time constraints, I was unable to pursue this line of study. Instead, I sought the perspective of family caregivers, as they were able to represent their elders with dementia and were witnesses to their care. Accordingly, I undertook a small study as described in the methodology section.

METHODOLOGY

The study's focus on understanding the experiences of those typically subordinated or silenced in official institutional discourse locates the research in a critical social science perspective (Neumann, 2003). The research was designed in order to understand the structural forces at work that excluded the voices of family caregivers, and to explicate the power relations at work that perpetuate the exclusion (Campbell and Gregor, 2002). The goal is to understand the forces at work that foster this exclusion. In accordance with this critical approach and building on feminist research practices (Neysmith 1995), I sought to locate myself clearly and reflexively in the research. Throughout the study, I was attentive to my own location, knowing that I am, in practice, steeped in a professional discourse about dementia care. Attentive to Campbell and Gregor's (2002) reminder that researchers be vigilant in order not to 'import' concepts from the dominant discourse on the topic of research, I needed to be alert to, and willing to be open to examination and surprises during the study process. I was, further, attentive to issues that I thought might arise because of my racialized identity as an Asian while accessing participants and interviewing 'across differences' (Narayan, 1994). I embarked on the study assuming that participants would be White and, based on my experience, that our differences might complicate or interrupt communication or be a consideration in their decisions to participate. Accordingly, I designed recruitment strategies in order to minimize potential tensions for them and for me.

In order to gain insight into the meaning and understanding of person centred care from families' perspectives, I used qualitative methods and carried out a small study based on semi-structured interviews. The approach to sampling, data collection and analysis are briefly described.

Sampling

A purposive sample (Mason, 1996) was sought through a community agency in Southern Ontario that provided services to families and persons with dementia. This particular agency was chosen as the research site as it is set up specifically for people with dementia and their caregivers. The agency provides support and information to people with dementia and their caregivers, raises public awareness and provides fund for research on Alzheimer's disease and related dementia. The agency also runs a variety of caregivers support groups, and families who attend these support groups have relatives who are receiving formal care, either through home care or through institutional care. I chose to recruit directly from these support groups as families who attended caregivers support groups were already comfortable talking about their experiences with others in different settings.

I deliberately negotiated with the agency to conduct a face-to-face group recruitment of participants at caregivers support groups, as I was conscious that working across racial differences might be a challenge for some participants and I did not want to surprise them if I were to choose an indirect method of recruitment. By conducting the

recruitment in this format, it allowed the group members, firstly, to see, ask questions and be comfortable with who I am. Secondly, it allowed me the opportunity to explain to group members the reasons why I was interested in doing this research project. By establishing a common interest with group members, what Pearce (1993) termed 'negotiating', it was my opinion that it would help to alleviate some uneasiness for group members as they deliberated over whether they would participate in my research project.

Presentations were made to one group of twelve (12) individuals who were attending a caregivers support group. These individuals had been identified by the community agency as families who had relatives with dementia and were receiving care, either at home care or in an institutional setting, and who had witnessed care being provided to their relative with dementia. During the presentations, I shared the purpose and goal of the study with group members and invited them to ask questions related to the study. Copies of the letter of information about the study were distributed to group members during the presentations and they were invited to contact the researcher directly if they were interested in being research participants.

Sampling description

Using this approach, three (3) participants were recruited for the study. All the participants were female and White and they ranged between 60-82 years old. Of the three women recruited, one had a full time paying job outside the home while the other two women were retired from their paid jobs outside the home. Two of the participants were wives of husbands living at home with them; one attended a day programme for people with dementia and the other was receiving home care services. The third participant was the daughter of a mother residing in a long-term care home.

Data collection and analysis

To promote participants' control and confidence in the protection of their privacy, they were provided with choices of interview locations. All the participants chose to have the interviews occur at their homes. The purpose, goal, risks and benefits of the research study were reviewed again with the participants and their consent formally obtained prior to the onset of the interview. A letter of information (see Appendix A) and a copy of the consent form (see Appendix B) about the study was provided to the participants. The rationale was that even though the participants had been given a copy of the letter of information during the recruitment phase, the assumption was that the participants might have misplaced it by the time the interview occurred.

The interviews lasted for approximately an hour each, were taped and transcribed, with participants' consent. The tapings of interviews were done to capture all the details of the participants' stories as shared with the researcher. An interview guide (see Appendix C) was used, including questions on their observations about the care that their relatives received, whether service providers were knowledgeable about their relatives' needs, values and preferences and whether their knowledge was put into care practices. Interviewing skills, such as reflecting back and rephrasing of participants' responses were

used during the interview to ensure that I understood participants' meaning and to draw forth examples and elaborations of experiences.

The transcripts were then analyzed using an "ad hoc" (Kvale, 1996, 203-204) approach in order to identify key themes. Practically, I read the transcripts several times to gather an overall impression and then re-read selected sections, to "bring out connections and structures" (Kvale, 1996, p. 204) salient to my research study. Conceptual ideas were then formulated from the themes/constructs (Miles and Huberman, 1994) generated to account for families' experiences of 'knowing'. In reporting the findings here, pseudonyms were used to maintain anonymity of participants.

Transferability of the analysis

Although small, the sample of experience studied here can offer insight into family caregivers' knowledge of relatives with dementia and of the complexities and exclusions structured into the boundary between formal and informal care. The analysis generated here can be considered conceptually transferable to other comparable contexts. Following Lincoln and Guba, the transferability of the findings from this study are dependent on the richness and texture of the description provided for the use of another reader (Lincoln and Guba, 1985 as cited in Greene, 1990, p. 237). Given the demographics of the sample, transferability to culturally diverse or male populations should be qualified. It must be noted too, that not all people with dementia have family members who are involved and knowledgeable about them. This study can claim only to give voice to those family caregivers who are involved and knowing, as their vantage point is another perspective that can be added to the knowledge and understanding of person centred care.

KNOWING AND UNKNOWNING CARE: FAMILY CAREGIVERS' PERSPECTIVE

The three study participants had a valuable mix of experiences of formal care (home care, respite care, day programme and institutional care) and with different familial relationships to people with dementia (two wives of husbands with dementia and one daughter of mother with dementia). Each of the participants had different assessments of what it means to know their relative with dementia. What they all had in common was that they were very engaged with their relative with dementia and very vigilant of the care meted out to them. The participants were all very highly motivated to represent and protect their relative from poor care. Indeed, their vigilance and motivations were reflected in their willingness to participate in this study. Together, the three participants spoke about their witnessing and negotiating of the boundary between formal and informal (own) care, between organizations and people's personal worlds. Their experiences of negotiating the boundary in order to ensure that care was provided in a 'knowing' way, respectful and fostering of their relatives' particularities and identity, thus seeking, in other words, to support what professionals call 'person centred care'. Their accounts provided a rich base from which to discern their experiences and assessments of 'person centred care'. In presenting them below, I have strived to give primacy to participants' voices to further enhance knowledge and understanding of 'knowing' in person centred care.

Establishing the position of 'knower': "I am the one that knows him best"

The participants were certain about their position as the 'knower'. As succinctly captured by one participant, "I am the one that knows him best." Another participant stated "...nobody's ever been that close to them as their wives." Their claims to 'knowing' came out of the different dimension of knowing the relative with dementia, based on their intimate connection as partners or parent-child and the complexities associated with those relationships. It enabled the participants to know the person with dementia, their particularities, preferences, likes, and dislikes in a unique way that was not easily discernible to those outside those relationships. This special way of knowing was reflected in the stories participants shared and they arose out of a special knowing that could only occur out of their certainty about their knowledge on their relative. Their knowledge clustered in several dimensions: biographical knowledge, experiential knowledge and care practice knowledge.

Keeping things in one spot was one of the first things but that was even before we knew he has Alzheimer's. All of his life, there have been several things that he could never keep track off, his keys, his gloves. ...He would forget where he left his bible so he had to keep, always put it here, and your keys always go there, your gloves always go here so over the years, we have been doing that. And he would

often leave his keys somewhere so I just pick them up and put them back where they belong because that is where he would go to get them.

... I tell them to do something, like what mom was doing. She would have breakfast and after she would lay down, she would get up and she would think, "Oh, it's morning. Time to change." They were leaving her clothes, instead of putting them in clothes closet, on the doorknob, so she would get up and she would think "Oh, there's my new clothes. It's morning." ... I said to them, "No, don't do that. Put them away in the closet because she's thinking morning all over again.

Such biographical knowledge spoke to the awareness and knowledge of the personal habits, rituals, personality traits and other personal particularities that participants had of their relatives. It enabled them to anticipate their actions as well as in using that knowledge to inform their own care practices with them. This knowledge, plus their experiential knowledge of caregiving, produced invaluable skills that they had as family caregivers to their relative with dementia. For another participant, her biographical knowledge of her husband guided her negotiation with him:

...He is so independent...I know when he goes, when he could walk across the street to the plaza, he didn't like them holding his arm or having them hold onto him or him hold onto them. Still doesn't let me. I tell him that I need it. I said, "Will you help me with these steps?" and then of course he will.

This participant's sensitivity to her husband's self-esteem and her skill in knowing how to negotiate with him to ensure success was a demonstration of the preservation of abilities that Perry and O'Connor (2002) found in their study of the different ways that spouses used to modify their expectations of their partners with dementia by focusing on their strengths. Hellstrom, Nolan and Lundh (2005) found similar findings. In this study, by 'knowing' the strengths that her husband had retained, his willingness and generosity to help, it enabled the participant to achieve her safety concern for him without jeopardizing his need for independence.

A common theme raised by all the participants was the expectation they had to be acknowledged as a 'knower', a position based on their intimate connection with their relative as well as in their experiential caregiving (Duncan and Morgan, 1994; O'Connor, 1996). They were the ones who knew and understood their relative. They were also the ones who noticed changes in their relative before a formal diagnosis of dementia was made:

... he made a couple of banking errors that we had to untangle and at that point, I had to start doing all of the banking and the financial things. He was always the financial guru and he was good at anything math...This was not the way he normally operated.

...we knew it was something...When he got to the stage when he was actually lost in the car... That year we went to the doctor. They didn't take his license the first

year. They said he had just marginal and they passed. But I knew it was a little, it was a little further than that because he was still getting lost. ...I knew it was really bad when he couldn't find our driveway, he would drive into the neighbour's driveway on one side or the other neighbour's driveway on the other side, miss our driveway and we had lived there 25 years

Participants' particular knowledge about their relatives enabled them to recognize and differentiate between what constituted normal and abnormal ways of functioning in the everyday lives of their relatives (O'Connor, 1996).

Prior to accessing formal services, participants had developed their own unique ways of caring derived from their own caregiving experience to their relative (Duncan and Morgan, 1994; Perry and O'Connor, 2002). These caring practices could be of immense value to service providers. As a participant explained:

...when he's looking for something, this is just an instance, he's walking around, he appears to be agitated and he's saying, "I can't find it" and he always refers to things in pronouns. He doesn't use nouns any more and I could get just get frustrated or walk away and if I get frustrated, then I do walk away because getting angry isn't going to help. What I found works better is just to stop and let him talk about it...

We have developed a lot of strategies around here as the situation presents itself, like these stickies on the counter. We've been doing that for a long, long, long term. And there's one for each day and it outlines what we do each day. He checks that numerous times...And when we pick out his clothes, we do that the night before and we hang them in the cupboard on the hangers in the same place every night so in the morning, he goes in and they're there. That's something that a caregiver would need to know. There's probably other things that we have learned to do automatically.

The participant saw herself as an 'expert' on her husband with dementia, particularly in the area of knowing and understanding what he needed. She cemented her 'knowing' position further by stating, "...I manage all of his care. I manage his life for him.... I could fill them in on a lot of information that they would need to know. They wouldn't have to find out by trial and error." It spoke to the wealth of knowledge, skills and experiences that she had of her husband and to the benefit of including her voice if care were to be provided in a tailored manner to meet his unique needs. All the participants in the study wished to be recognized for the knowledge they had of their relatives with dementia. They also wanted to be accepted as involved family caregivers in the ongoing care of their relative with dementia, a notion supported in several studies (Duncan and Morgan, 1994, p. 240; O'Connor, 1996; Friedemann, Montgomery, Maiberger and Smith, 1997; Train et al. 2005).

Enabling knowing care

One of the questions asked of study participants was how and when family caregivers were able to share their knowledge on their relative with service providers to enable knowing care. Participants identified different ways in which this occurred that included both formal and informal processes. As one participant shared:

And the initial interview, when we went in to book him into the day program, was very thorough, quite long. They needed the medical history, of course, and his background, his life and where he had been, what he had done, where he grew up. They make what they call a memory book there, his isn't finished yet, and they put pictures in it and stories of the person's life and they get them out and look at them when they're over there and they keep it there... So that it helps the patient have security of knowing. And they went out of their way to learn about his background and what he had done.

In this formal procedure of knowledge transfer, service providers actively sought out or invited the participant to share her knowledge on her husband at the system mandated interview. Formal gathering of knowledge was done for a specific outcome and in the initial interview, the outcome was the completion of a tool, a memory book, which service providers used to begin the process of getting to know him. In studies that looked at 'person centred care' (Kitwood, 1997; Brooker, 2007), getting to know the values, needs and preferences of people with dementia all served to inform person centred care.

In this study, participants used more informal than formal ways to transfer their knowledge of their relatives, choosing moments and opportunities to proffer or insert their knowledge during informal interactions with service providers, such as leaving written notes for service providers. One participant commented that she always left written notes for service providers when she was not at home during their visits, thus indicating her use of the written medium as a form of communication with them. Other participants used the more conventional way, which is the verbal form:

...they said you can send them a letter and you can send them your history, anything about him that would get the staff to know him. I said, "Well, he's written a story. She said, "Marvellous, bring it down."

Like she (*participant's mother*) thought she worked in the nursing home. So she (*the staff*) asked me. I said, "No, she worked at the Henderson Hospital on the chronic wing," I said "but when the chronic wing closed, she went to St. Peter's and worked there until she retired." "But that's good to know", she (*the staff*) said, "cause we didn't know to believe her or not."

In contrast, one participant chose to demonstrate or model her knowledge to service providers in her mother's care facility. This method was a more assertive form of communication as it was a public act, done with the intent to push the knowledge at service providers:

I put pictures. I made pictures of all the, like all my brothers and sisters on the wall and I got her grandchildren and she tells the nurse all about them. I decorate her little room for Christmas, her birthday and stuff like that...because she loved to decorate at Christmas and all the stuff like that...

Through these various forms of transferring knowledge to service providers, participants alerted me conceptually to the notion that the process of knowing people with dementia is a dynamic process and not static or 'once and for all':

...a care provider would need to be ...gentle and find out what this person is like. It would be more time consuming. Just being with the person. Like they would find out little by little each time they came.

I think if they had built up, if someone would build up a relationship, never mind the care. And have tea with and cookies, biscuits, something that builds up a relationship.

As the participants stated, 'telling' and 'knowing' is a social and dynamic process, and it is dependent on the nature of the relationship between participants, service providers and the person with dementia. Time and stability of relationship are essential components for the relationship to move to another level of telling and knowing (Gantert, McWilliam, Ward-Griffin and Allen, 2008):

One of the things that they found that he likes to do is colour. Which is interesting. He brought home just a plain black and white outline picture. He started to colour over there with magic markers and he sat here with our magic markers and worked and worked and worked on it and it's quite the activity. He worked for hours here at home... And that's interesting to see him doing it. He's doing it with detail and diligence like he always did his work...and when he brought it in to show them, they were very interested and complimented and praised him for the work that he had done.

When a relationship reached a level of trust, there was comfort and confidence in the information exchanged between the parties. In the above interaction, the idea of an elder engaging in the 'childish' act of colouring may be offensive, but not to the participant. It was evident that she trusted the knowledge of the service providers who provided that as an activity for him. I was a bit disconcerted when I first heard her story of her husband engaging in the 'childish' act of colouring. I felt that he was being 'infantilized' and a victim of marginalization, a concept that went against all the beliefs and values I hold as a person and social worker. At that time, I chose not to address it and was glad as the story unfolded to reveal the participant's skill, insider knowledge and capacity to see beyond the immediate, to see that the simple act of colouring also revealed the 'personhood' of her husband to her. It was a testament also to her implicit

trust that service providers must know her husband's prior values, preferences and needs to have engaged him in that activity.

Participants also persisted in proffering the knowledge they had of their relative informally, as exemplified by a participant whose husband had been receiving home support services for a number of years:

He doesn't play cards. He doesn't play board games. He might do it a little more now...I am trying to think of something they could do together...Now one of the things he has written his story, his life story, up to the time when he and I met and when I read it to him, he just loves it. Now if someone would read his story to him...Now if they came with some kind of a kit for dementia of things they could do together...they could read his story and they would only have to read just a chapter at a time, just come in every morning and read a chapter and then get on with the work that would get to know him.

The creative strategies that the participant thought of to enable knowing care spoke to the hope she had that care could be improved, despite her negative experiences with the services to date.

From the position of 'knower', participants also saw themselves as well qualified to speak to approaches that enhanced 'person centred care'. This 'insider' knowledge was grounded in their first hand experience as caregivers:

They would need to know, get to know a lot about him, what his background is, where he came from, what he did. His likes and dislikes. It would need to be the same people...Instead of a different one everyday, different, different, different. It's extremely important that that is stable and regular and as much as possible, the same people come to that home or the same one, or maybe two, so that you don't have a total stranger each time.

I would say that they should get to be his friend first before they start to try to take care of him. Get...build up a rapport with the person, with him, with the patient. Never mind the physical needs as much as getting, building up a trust so that then he gets to trust you...Getting to know the person as a person first, then adding the care...instead of coming in with the sponges and the mops...

The common message that participants highlighted here is the importance of establishing a relationship with the individual with dementia, an essential step to building trust between the service providers and the person if care is to be provided in a knowing, personal and respectful way (Hartrick, 1997; Pedlar and Bregel, 1999; Mok and Chiu, 2004).

Unknowning care: 'a link that is missing'

One participant shared her experience of going through a formal interview with a service agency: "...they ask about his health, like his mental abilities and all that but not about his personal ...". To provide 'person centred care', service providers need to acquire knowledge of the person with dementia, knowledge that will inform them of the person's particularities, likes and dislikes (Kitwood, 1997). This can only happen if care institutions and service providers are deliberate and intentional in their approach to seek to know the 'person behind the illness'. The focus on health, the biomedical model, disregarded the person with dementia as an individual with lived experiences. By overlooking the person, caregiving becomes depersonalized and the individual preferences, likes and dislikes disregarded. The dissemination of knowledge gathered to the frontline service providers is also crucial to enable personal care. One participant spoke of the time she spent sharing her knowledge with service providers and stated bluntly: "...but that's all at the office and it doesn't seem to move into the relationship with caregiver."

When caregiving is task-focused, unknowing care is the outcome. As one participant commented:

They can't converse with him, ... and they don't try to draw him out. If he just wants to stay in bed all the time they are here, they said 'That's fine'.
...they do the dusting and the dishes and the bathroom and shower him and see that he gets his change of clothes back on and then he goes back to bed.

The focus on functional tasks objectified the person with dementia, an act that Kitwood (1997) and Brooker (2007) saw as a devaluing of the person. Studies had shown that the devaluing of a person with dementia occurred when the focus of care was on the completion of instrumental tasks (Duncan and Morgan 1994; Aronson and Neysmith, 1996; Aronson, 2002; McCabe, 2004).

Unknowning care also persisted when there is no relationship between service providers and the people with dementia. This concept was brought forth by a participant when she was asked about her husband's response to care:

...they leave me a note and say "He refused to allow me to shave him" but I think that's cause they don't get to know him"...I think if they had built up, if someone would build up a relationship. Never mind the care. And have tea with and cookies, biscuits, something that builds up a relationship.

The refusal of her husband to have his care completed was indicative of the lack of trust in the caregiving relationship. Pedlar and Bregel (1999) and Mok and Chiu (2004) found that trust was essential in caregiving context. Without trust, impersonal care could lead to resistance or refusal of care (Sloane et al 2004).

Besides the need to have trust in the care giving relationship, service providers must have education and training in dementia care approaches. Without training, service

providers could provide care in unknowing ways without the realization that their care was destabilizing the very clients they were trying to help:

Now I saw one girl, the girl and she liked him quite well. He liked her. He got use to her after a couple of years and I was here when all of a sudden, and he was sitting in his chair, she took off his glasses like that and he was shocked because his glasses, he can't see without them and he's just terrified if anything should happen, but rather than to say "I'm going to take your glasses off to clean them now", she just snapped them off.

...they want to talk to me you know... about how things are and what they're doing and what I'm doing and where I've been and all that, I mean, it's like Cliff doesn't exist.

The unskilled care provision and "depersonalizing tendencies" were what Kitwood (1997) labelled as "social malignant psychology" (p. 47), a term he coined to capture any act that undermined the 'personhood' of the person with dementia. According to Kitwood (1997), 'personhood' is defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust." (p. 8). Thus, in the context of care being rendered by unskilled service providers, they had engaged in the practice of 'malignant social psychology'. It speaks to the pivotal need for the education and training of service providers to ensure care provision that honours the 'personhood' of the people with dementia. This training need was echoed by one participant: "I think it comes in the training... Train the people to talk to people with Alzheimer's. ...Alzheimer's is a specific kind so the people that are going to be attending Alzheimer's (*clients*) ...they'd all need to be trained."

When unskilled care is meted out to people with dementia and it is being met with resistance or care refusal, they may be labelled as difficult or uncooperative. One participant reflected how she had bought into the labelling of her husband, believing that he was the problem: "I forgot to look at them and say they should be drawing him. I thought it was him who was being uncooperative." The call to provide education and training for all who provide care to people with dementia (Dupuis and Smale, 2004) is essential to prevent further marginalization of people with dementia. In the words of one participant, unknowing care occurs when there is "... a link that is missing..." between knowledge and practice at the frontline.

Unknowing care: family caregivers' responses

Participants interviewed were resourceful and creative individuals who learned from their experiences of caring for their relatives with dementia to be persistent in offering information about their relative to service providers. However, when the conventional ways of communicating information failed to garner the result that they had hoped for, they became advocates for their relative and resorted to other forms to communicate what they knew about their relative. In this study, three main themes

emerged to reveal the ways that participants dealt with unknowing care: 'taking charge', 'refusal of services' and 'complain/don't complain'. One participant who herself worked in a long-term care home, took the 'taking charge' mode after the conventional methods failed to produce the result she wanted:

So I phoned... and said "I hate to be a bug...but they are not using the pull-ups that I am supplying to them." "I am going to email them again." I said "I hate to be a pest." She said, "No, you are no pest... because they ought to be doing that." So what I done one night, I brought home all her underpants. I left maybe 3 or 4 pair and I put all the pull-ups there. Well now, she has got them on all the time. What I do now I take, put them in her drawer so when they go for underpants, they automatically pull out the pull-ups and put them on her.

The 'taking charge' mode was an assertive approach that situated the participant in a position of control. By removing the underpants, service providers were left without a choice but to use what was available. As reported by the participant following her action: "So that's what they do now." From the participant's point of view, this effectively solved the problem for her and ensured that her mother's particular need would be met. What is particularly interesting is that studies (Gladstone, 2000; Reid, Chappell and Gish, 2007) into family roles in institutional care showed that their ability to take charge was diminished as they were fearful of being seen as interfering by nursing staff but this was not reflected in this study. I would speculate that this participant's professional working experience within the long-term care system was the influencing factor here.

The 'refusal of services' action was taken by one participant as a way to protect and minimize the negative impact on her husband after witnessing 'unknowing' care being provided.

...they've asked...me if I would like more hours. They keep asking me cause it's been all this time and I still have two hours a week after 5, 4 years, 2 hours a week. ...And I just... I can't see any point in getting them in to do more dusting or vacuuming while ... sleeps.

The 'holding out' against services (O'Connor, 1996) may be constructed as an active protest against the impersonal nature of caregiving meted out to her husband, an action that the participant could have control over instead of subjecting her husband to further depersonalizing and disabling care. The participant recognized the futility of handing over more of her caregiving responsibilities when it did not provide the relief for her or the benefit to her husband. As she stated, "if he doesn't build up a relationship with somebody, he will only have me looking after him."

Another participant chose to 'complain' about the inferior care by taking her concerns directly to the service agency:

The girl phoned me in the morning, the people who were caring for him overnight called me in the morning, ...I said, "How did he do?" and they said "He slept well

but he refused any personal care.” Really angry like. And so I told them that they should feel that if he doesn’t need personal care, good for him..., it got my back up a little bit... so I called them...and said “Who looks after these people at night when ...all the day staff are gone?... they attacked me because he wouldn’t let them look after him. Who do they answer to?” She said, “Well, nobody. We don’t have a night supervisor on.” So they are hiring one... somebody in charge of those girls who stay up all night with them.

The participant’s decision to take the concerns directly to the service agency came out of her sense of outrage at the lack of respect shown to her husband. Her immediate instinct was to defend the actions of her husband as a way to protect him from ‘unknowing’ care. Such expression of advocacy revealed the role that family caregivers take on as a representative to their relative with dementia (Bern-Klug and Forbes-Thompson, 2008).

Choosing ‘not to complain’ was an avenue that one participant chose to follow:

Oh my gosh, I wouldn’t even want to approach them cause they would lose me as a client if I ever complained, I feel. I think as nice as the caregiver, the agency is and she is really nice to me cause I never complain ...he did go 2 days without anybody coming when I went away cause they said they couldn’t get in and that was our regular girl...She never came back to us after that. But I didn’t complain. I just said, “Well, just send us a new person... If I say anything, they will give us a new person. There’ll be another new person for him to get use to.

Two main points are shown here to explain why the participant was reluctant to take action to address her concerns about ‘unknowing’ care with the service agency. Firstly, the desire to protect her husband from having to endure another change, another ‘new person’ to get use to, was a strong incentive to avoid taking action. She stoically dealt with the situation when she found out that her husband was left unattended for two days. Secondly, there was a consciousness about the need to protect her social reputation, that when someone ‘is nice’ to her, there was the societal expectation that one did not reciprocate by complaining about him/her. The fear of jeopardizing the ‘niceness’ was clear from the exchange between the interviewer and the participant further on in the interview:

Participant: She told me, she said if ...still refuses to have a shower, the care will be cut off. It was her that told me that. She said unless you agree to have a shower, the care will be cut off. Now I believe that concern went to the CCAC and I believe they did change it... They changed the rule. I think you can have care without taking, having a shower given or a bath.

Interviewer: That’s good that you brought forward that concern.

Participant: It wasn’t me. It wasn’t me. It was somebody else because I, they talk about it at support group at Alzheimer’s a lot.

The participant chose to dissociate herself from the positive change that happened within the home care system and attributed it to 'they', other members of the support group, in her attempt to continue to preserve her reputation as someone who does not complain. Besides the two reasons brought up by this participant, other factors may impede family caregivers from taking action. There is the fear of jeopardizing the services already provided, the futility in voicing complaint and concern for their service providers (Aronson, 2003; Aronson 2006). Family caregivers may also feel that they do not have the options available to them based on their social location such as gender, social class and race.

Unknowning care: consequences to people with dementia and family caregivers

...he was a guitarist and an entertainer, a singer. He's got a beautiful voice and he used to go around nursing homes and before, when he was young, he was in a band but he used to go around nursing homes and entertain. He just loved to do that. ... I thought, well, his guitar will be the bond in the future but the first lady (*service provider*) that came spotted the guitar and wanted him to play it, that was a good thing and he did but right away she wanted him to teach her. Well then, he got frustrated because he couldn't teach anybody and he put the guitar away. He didn't want to see her or the guitar any more....that was a fatal thing.

In narrating this account of unknowing care meted out to her husband, I could feel the participant's grief and helpless anger at the unskilled care that her husband received and the consequence for him. At the same time, there was almost a fatalistic acceptance of the way things were done despite her anger. The literature had shown that when the abilities of people with dementia were ignored, it left them with low self-esteem, contributing to a further deterioration of their remaining abilities (Kitwood, 1997; Brooker, 2007).

In contrast, when care was provided in a supportive and knowing manner, it culminated in the inclusion of the person with dementia in the everyday life events:

Participant: ...the day programmes are good and they are good for him. The programmes are excellent and ...he looks forward to that day. And he comes home, doesn't want to go to bed. He's wide awake.
...that's great...

Interviewer: What does it mean to see him like that?

Participant: Oh, wonderful, wonderful. And I know that he is capable of it. We go away to the States every, sometimes once a month with our daughters. They take us and do you know that he is like a different person. I said I think he is the biggest con artist in the world because when he is over there, he is a totally different person. But he has a relationship with us...And we are doing things. We are going out to

eat and we are walking and we are talking and we are joking and laughing and he is part of it.

It confirmed to the participant that her husband had more abilities than he may present to those who do not know him. Those abilities emerged as his family knew him, his abilities and interests, as well as being inclusive in their approach to him. As Nolan, Ryan, Enderby and Reid (2002) stated, “social inclusion is a precondition of personhood” (p. 199).

Damage to the self-esteem of the individual also resulted when the individual with dementia had no control over his care, an act that occurred within the context of service provider’s failure to know and meet his preferences:

He lets them do it but he’s angry. He doesn’t like it. I can tell he doesn’t like it. And he wants to get back into bed and get away from them as quickly as possible.

Subjecting the individual with dementia to care that is disrespectful often does not achieve the outcome intended, that is care completion, and it further decreases the emotional well being of the individual. The sense of helpless anger experienced by the care recipient was evident by his inability to stop the unknowing care and it led to his overwhelming desire to hide from the source of his embarrassment. This process of disempowering the person with dementia (McWilliam, Brown, Carmichael and Lehman, 1994; Goldsmith, 2002) is an example of unknown care being completed at the expense of the person with dementia and runs counter to the philosophy of ‘person centred care’.

‘Unknowing’ care can also contribute to the sense of insecurity and fear in people with dementia:

...he is so unsure, he just shakes. He is so afraid and he is afraid getting into that tub and when a new person, he is so insecure. He is so afraid that he will fall and a new person has him, like now we have another new girl, he is not happy cause he doesn’t know how to get in the shower.

As revealed by the participant’s story about her husband’s reaction to change with new service provider, due to their decreasing ability to process and cope with new information, any change in routine or familiar people is a major disruption for people with dementia.

For family caregivers, the consequences of witnessing ‘unknowing’ care can have several unintended outcomes. From the position as ‘knower’, their knowing can be a double-edged sword for them. As noted by one participant:

...my job now is caring for him and what else I do is peripheral, that’s around the side and it fits in where it fits in to my major job, which is looking after him. And my, I ‘m the one that knows him best. He’s most comfortable here at home so he won’t go to a long-term care until he’s... so until the disease has caused so much disability that he couldn’t be cared for at home. But with support, he could stay

here for a very long time. ...The only scary thing about it is if I got sick, so its extremely important that I don't get sick, that I stay healthy...

The familiarity of home environment and the knowledge that family caregivers have of the particularities of their relative with dementia are ingredients that makes for pleasant and comforting care receiving experiences for the individual. However, family caregivers have the task of balancing the care needs of their relatives with dementia and their own needs (O'Connor, 1996); compounded further when 'unknowing' care was meted out to their relative. One participant spoke of a desire to increase service utilization to enable her with her caregiving role to her husband but it was conditional on him being able to form a 'knowing' relationship with service providers:

...had someone that he could interact with, I would have them another day a week because it would be, I would go out and I would know that he was getting stimulated instead of going to bed.

I think he would relate to a male in that they would talk. I think that would bring him out. Females, he thinks, are just...like nurses or housekeepers...but not really friends.

When there was a perception of disconnection between what the participant identified as the services she needed for her husband and services available, it led to her decision to not utilize more of the services available to him. From her perspective, to use more of the services served only to benefit her and not her husband, a move that she could not entertain due to feelings of guilt. Studies have found that family caregivers were more apt to decline services that were not in line with their perceived needs and system inflexibility to meet their changing needs (MaloneBeach, Zarit and Spore, 1992; O'Connor, 1996). It speaks to the need to look at services that are flexible and responsive to the needs of both the caregiver and the person with dementia as a family unit (Dupuis, Epp and Smale, 2004). Practically for the participant, witnessing unknowing care served to foreground the reality of institutional care for her husband:

Well, probably his care in a long-term care would be better than it is in, like an apartment. His care might be better and he would be more stimulated as well...

In the participant's desire to find quality care for her husband, institutional care was considered as an option, an idea that was probably hastened as a result of the impersonal care that he had received at home from formal service providers. At the same time, there was some uncertainty about her decision, and with her awareness of my professional work in dementia work, I had wondered if she was seeking for some affirmation from me to validate her decision. Research has shown that when home support services were available and meeting the needs of family caregivers and people with dementia, institutional care might be delayed (Vernooj-Dassen, 1995, as cited in Zarit, Gaugler and Jarrott, 1999; Gaugler et al., 2000).

On an emotional level, the guilt and remorse that one participant spoke of as she reflected over the care that her husband received, was palpable: "I just didn't realize that he's so unhappy and maybe there is another way around it. I am just taking, accepting it." In her attempt to balance her need for respite from caregiving against the needs of her husband (O'Connor, 1996) there was also self-blaming for acquiescing to her need and the dominant discourse of caregiving as a 'burden': "...they're giving me a break. So I'm getting the break....They told me keep on trying. They said he'll never be willing. You just have to make that decision for him..."

The emotional tension was also evident for one participant when she negotiated for formal support services to help her in the caregiving of her husband with dementia and carrying the burden of feeling that she was personally responsible for upsetting him:

...the next lady didn't speak very good English and ...couldn't understand her at all but she had a way that got him into the shower...He was upset. I think he didn't talk to me for a while. You can tell he's upset. He doesn't want to watch TV with me or stay up in the evening or anything.

The difficulty for this participant was her helplessness in ameliorating the situation for her husband and herself, without having to resort to the last option available to them, which is institutional care, an idea that is very stressful for her : "...it's so hard to have to do that. To send somebody somewhere where they don't want to go." The emotions revealed here highlighted the tensions that family caregivers of people with dementia encountered on a regular basis as they navigate the different challenges and decisions (O'Connor, 1996; Dupuis and Smale, 2004) they have to make that arose out of bearing witness to unknowing care.

DISCUSSION

Knowledge and practice

In this study of the meaning of person centred care from family caregivers' perspectives, participants were particularly articulate in sharing their experiences, stories and interpersonal encounters that shaped their understanding. Such clear articulation by the participants gave me much insight into the conceptualization of person-centred care from family caregivers' lens and served to highlight the crucial role that they can, and should play, as active participants in the care of people with dementia.

The study showed that in order to improve care delivery to individuals with dementia, health and social care professionals must get to know the person with dementia as it is only through the relational context that the values, needs and preferences of the individual can be known. It is therefore incumbent on health and social care professionals to make an intentional and deliberate effort to know the person with dementia, a process, family caregivers in this study and other studies (Kitwood, 1997; Brooker, 2007) maintained, is the central tenet in person centred care. The implication for frontline staff, including social workers, is that when working with people with dementia who are too far along in their dementia illness to be able to identify and communicate their values, needs and preferences, involved family caregivers are good sources of information. By soliciting and procuring from family caregivers their knowledge of their relative, health and social care professionals will be able to develop individualized care plans that incorporate the medical as well as the social dimensions of care and that are attentive to the historical and cultural specificity of that knowledge.

The accounts of participants in this study indicate that the philosophy of person centred care as envisioned by Kitwood (1997) is not what is being practiced at the frontline. What contributes to the dissonance in knowledge and practice and what can be implemented to remedy the discord? According to Vittoria (1998), it requires a critical approach to examine the underlying assumptions of dementia care, to focus less on the techniques of care and behavioural management and more on principles that inform the current work, philosophy and approach to dementia care. Assumptions are manifested in the details of daily practice, in the language and in the rendering of care (ibid, p. 132). As this study revealed, assumptions were embedded in the practice of formal care providers and set the tone in how they interacted with persons with dementia and family caregivers. To address the dissonance between knowledge and practice, health and social care organizations that claim to practice person centred care can benefit from examining 'taken for granted' assumptions that guide their views and approaches to persons with dementia and dementia care, and in their allocation of resources, such as consistent staff, education and training, to support that claim.

We also need to realise that any claim to person centred care cannot be achieved without the inclusion of families of people with dementia who are, generally, most knowledgeable about them (O'Connor, 1996, Nolan, Ingram and Watson, 2002). It speaks to a collaborative approach that hinges on relationship development between formal care providers, families and the people with dementia (Robison, et al. 2004) and

the need to equalize power differences between the parties (Clarke, 1999) as we strive to provide quality dementia care. We need to seek out, accept and incorporate knowledge of involved caregivers of their relative with dementia into daily practices. This study has shown that involved family caregivers were intimately knowledgeable of their relatives with dementia and well equipped to speak to their values, needs and preferences. Dementia care professionals can learn from family caregivers as these participating caregivers showed they had the experiential and biographical knowledge to guide knowing care. It serves to highlight to professionals that techniques and interactions in care processes require interpretation within the biographical context of the person with dementia. Yet the power differential between family caregivers and formal care providers situate them as “ancillary to the patient, part of the background but not within the remit of practice” (Twigg and Atkin, 1999, p. 139).

Barriers to foregrounding of family caregivers’ knowledge

Despite the invaluable knowledge that family caregivers can bring to improve the practice of person centred care, their knowledge and perspectives generally remain excluded. This exclusion can be traced to inadequate resources that confront health and social care agencies. In fact, this study revealed that the focus on a task centred approach had serious consequences for family caregivers and their relatives with dementia, even to the extent of dissuading them from utilizing services. A task centred approach to care does not require service providers to know the person with dementia as ‘the person becomes the means for accomplishing the task, rather than the reason for doing it’ (McLean, 2007, p. 181). This means that people with dementia continue to be depersonalized and invisible, without a voice to represent them and, as shown in this study, family caregivers are similarly rendered voiceless by the structures in health and social care sectors.

The results of this study suggest a need for enhanced community and institutional care resources to enable person centred care. The realities of contemporary efficiency-driven health and community care services do not, however, provide the material or political conditions for such enhancement. Importantly, though, these realities can be shifted: they can be responsive to negative public opinion and, as noted in the introduction, are energetically contested by public health care advocates. As social workers are trained and skilled in advocacy, they can play crucial roles in helping to “politicize” (Baines, 2007) the deteriorating care being meted out to elders at home or in institutional care. This can be in the form of drawing links with social/political movements and in critical consciousness-raising with concerned medical, health and social care professionals. Through these practices, social workers can question and challenge the dominant discourse that serves to subjugate the vulnerable and the sick in society.

In addition to the challenges posed by insufficient resources in long term care, the other barrier that this study revealed was the subordination of involved family caregivers’ ‘unauthorized’ knowledge (Campbell and Gregor, 2002) to the professional and medical discourses on dementia care. Medical, health and social care professionals are viewed as

‘experts’ in dementia care. Their knowledge bases are more highly valued and therefore prevail over other less valued perspectives, such as those of family caregivers (Clarke, 1999). The use of professional language by these professionals makes it difficult for the language to be easily comprehensible to family caregivers (Campbell and Gregor, 2002), thus serving to exclude them from participation in decision-making or in the everyday activities of their relative with dementia.

In the reality of today’s increasing focus on efficiency and accountability, including and translating dynamic knowledge gained from family caregivers into institutional processes is a challenge for social workers working in the health care system. The effects of health care restructuring in Ontario in the mid 1990s are still being felt as social workers face the ‘thinning’ out of their professional skills, the loss of professional autonomy, increases in job responsibilities that mean a higher volume and more complex caseloads (Globerman et al., 2002). “The tyranny of unrelenting acceleration” (Garrett, 2003, p. 455) typifies the pace of frontline social workers who are pushed to do more with less in meeting the demands for services, both internal and external to the hospital. In that regard, social workers are not able to do the work they trained to do, including advocacy against exclusionary practices in dementia care.

There are important implications for social workers. As frontline staff, social workers are well situated to mitigate the oppressive structures that serve to limit the involvement of family caregivers who want to be part of the team that care for their relative with dementia. Despite systemic and organizational challenges that impede the inclusion of family caregivers in dementia care, and that constrain the practice of social work, social workers need to continue to develop a critical lens and a willingness to work with these tensions, to understand them and to find ways to respond to them in order to bring about changes that will benefit those with dementia and their family caregivers. In the first instance, the practice of using professional language with family caregivers at family meetings or case conferences needs to be questioned. The language and format of the meeting may be a deterrent to full participation by family caregivers. To demystify the professional language and enable family caregivers’ participation, social workers can assume the role of interpreter to family caregivers and by modelling in the use of ‘lay’ language in these meetings.

At the individual practice level, social workers can empower involved family caregivers by equipping them with “strategies specific to bureaucratic settings” (Baines, 2007, p. 56), by teaching them to speak and interact with professionals in ways that would allow their voices to be heard. Additionally, by recognizing the power differences family caregivers face in health and social care sectors, social workers can use that knowledge and their privileged positions as professionals to facilitate successful outcomes for some family caregivers who lack the skills needed to negotiate with medical, health and social care professionals.

Identifying instances of exclusion is another important task for social workers who are skilled in communicating and negotiating with health and social care professionals. Through this process of ‘naming’ (O’Connor, 1996), social workers can enable these professionals to become aware of their clinical practices, particularly in relation to family caregivers. As discussed in this section, there are assumptions that

guide the daily work of professionals and by raising awareness to the underlying assumptions that inform their practices, social workers can help other professionals to identify instances of inclusionary and exclusionary practices.

Besides the use of 'naming' to identify exclusionary practices by health and social care professionals, that process also requires social workers to be vigilant in examining their own practices, and in the use of the professional language in their clinical encounters with family caregivers. As Campbell and Gregor (2002) maintained, professional language is a tool used by organizations to control the practices of its workers to perpetuate the "authorized view" (Campbell and Gregor, 2002, p. 22). By choosing to 'name' their practices and language, social workers can be cognizant of hidden assumptions that govern their practices and language. They can stand apart as critics of the 'authorized view' to challenge the assumptions held and the power it has in governing work practices that limits participation of family caregivers in dementia care. Social workers can also affect "small victories" (Aronson and Sammon, 2000, p. 183) in the day to day practices with family caregivers and formal care providers, in single act of advocacy, such as working with nursing staff to change a bathing routine or in providing choices of beverage to a person with dementia.

At a macro level, "forging ties and alliance beyond the boundaries of the workplace" (Aronson and Sammon, 2000, p. 183) to other service organizations can also help to foster the critical mass needed for medical, health and social care organizations to recognize and accept the valuable view of family caregivers in person centred care. As noted in the introduction, a range of organizations and professional groups are engaged in pressing for more adequate resources in long-term care, particularly for continuity in staffing in home and institutional care contexts. As an organization that has been established to meet the needs of family caregivers and people with dementia, the Alzheimer Society can play a greater role in providing support and advocacy for greater participation and involvement of these individuals in matters relating to the philosophy and delivery of dementia care.

As the greying of Canada progresses, the need for dementia care will increase. It will call for concerted action by concerned citizens, formal and informal care providers, academics, policy makers and people with dementia to work in alliance and press for policies and practices that are inclusive and that are truly knowledgeable about those most affected: those with dementia and the family caregivers who represent them.

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Appendix 1

LETTER OF INFORMATION

Research Study: “Person-Centred” Care of People with Dementia: Families’ Perspective.

PURPOSE OF THE STUDY:

People with dementia are individuals who have led full and varied lives. They are individuals who have unique life stories, who require sensitive and purposeful contacts with others, and who deserve to live in an environment that supports their wellbeing. To provide quality dementia care, care providers need to know and understand the person behind the dementia.

While a “person centred” approach is seen as the standard in dementia care, it is not widely studied or understood from the family’s perspective. Families are the ones who know their relatives with dementia. The purpose of this study is to gather insight from you in the hopes of contributing to our understanding of “person centred care”, as well as to improve service provision to people with dementia.

Are you a family member of a person with dementia who receives care at home or at a long-term care facility? You can provide a unique perspective on the care provided to your family member based on your knowledge and your experience.

This letter invites you to consider participating in this study which I am conducting as part of the requirement for my Masters degree in Social Work at McMaster University. I would like to provide you with information about this study so that you can decide if you want to participate.

PROCEDURE:

Participation would involve the following:

1) The interviews would:

- last approximately one hour.
- include questions about how you evaluate your relative’s care: how well care providers know him/her, whether their care is personalized/tailored to their needs etc,
- be audio taped (with your permission) and transcribed to allow me to have an accurate record of the interview.
- take place at a location convenient for you (I could come to your home, or we could meet at a local public library, a quiet café, the Alzheimer’s Society, or McMaster University)

RISKS AND BENEFITS:

You may find reflecting on your family member’s experiences and your own emotionally up-setting. If you decide to participate, you may choose to decline to answer any question asked in the interview that makes you uncomfortable or that you would prefer not to answer. You can also choose to end the interview at any time without consequence.

You may also worry about how others will react to what you say. Please be assured that any information you provide will be strictly confidential. Your name and any identifying information will not appear in any written report resulting from this study. However, anonymous quotations may be used.

Participating in this research study will not benefit you directly but by sharing your stories and experiences, it will provide valuable information that will deepen our knowledge and understanding of “person centred care” and may contribute to improving the delivery of services to people with dementia.

Your participation in this study is voluntary. If you decide to participate, you can withdraw at any time without consequences by notifying me via telephone or email. When you withdraw, any information you have provided will be destroyed unless you indicate otherwise.

Data collected from this study will be retained for a period of 12 months in a locked cabinet in my home office. At that point, I will destroy the data.

If you would like to participate in this research study, or have any question about the study, please contact me at ongswan@gmail.com or by telephone at 905-628-4601. Questions about the study may also be directed to Dr. Jane Aronson, my research supervisor, and she can be reached at 905-525-9140 ext. 23783 or aronsonj@mcmaster.ca

This research study has been approved by the McMaster Research Ethics Board. If you have any concern or question about your rights or participation in this study, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: 905-525-9140 ext. 23142
c/o Office of Research Services
Email: ethicsoffice@mcmaster.ca

Thank you for taking the time to read this letter of information.

Sincerely,
Siew Ong
Principal investigator and M.S.W candidate
School of Social Work,
McMaster University, Hamilton, Ontario.

Appendix 2

Research Study: "Person-Centred" Care of People with Dementia: Families' Perspective

Consent Form

Student Investigator:

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905-525-9140 ext. 23783
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I agree to take part in this research study exploring the meaning of "person-centred" care from the perspective of families of people with dementia. I have been fully informed about this study and understand its purpose. I have been provided with both a copy of the Letter of Information and this Consent Form to keep for my records.

I agree to take part in the individual interview that will last approximately an hour.

☐ I am willing to have the interview audio taped and transcribed.

☐ I am not willing to have the interview audio taped and transcribed

I understand that I can decline to answer any question at any time during the interview. I also understand that my participation in this study is voluntary and that if I decide to participate, I can withdraw at any time without consequences by notifying Siew Ong, the principal investigator. I understand that if I withdraw, any information that I have provided will be destroyed unless I indicate otherwise.

I have read the letter of information provided by Siew Ong about this study and have had the opportunity to ask questions about it. I understand that the researcher will keep my data confidential and my identity will not be revealed in any report. I understand that I will not receive any direct benefit from participating in this study. However, my participation will contribute to the knowledge base in "person-centred" care, which may help to improve service delivery to people with dementia.

I understand that McMaster Research Ethics Board has approved this study and that if I have any concerns or questions about my rights as a participant, I can contact

McMaster Research Ethics Board Secretariat
Telephone: 905-525-9140 ext. 23142
c/o Office of Research Services
Email: ethicsoffice@mcmaster.ca

Participant Signature: _____ Date: _____

Appendix 3

INTERVIEW GUIDE

Interviews will explore the broad areas for which questions and probes are mapped out below:

The process of your relative's illness and care:

1. Can you tell me about your relative's dementia journey...?
 - when you first noticed that there were some changes in memory
 - when it became clear that he/ she needed formal care and support
 - the kind of care he/ she received initially (home care, long term care facility etc), how did that develop, what kind of care does he/ she currently receive?

Your observations about the care that your relative has received/ receives:

A common concern for family caregivers is that their relative may get 'lost' in the routines of formal care provision, that they won't be known as individuals and their care tailored accordingly ...

2. Do you feel that care providers are knowledgeable about his/ her life, interests, preferences? Does the care reflect the person you know? (Probe for examples: when care is personalized and knowledgeable and when it is not, the differences, the signs)
3. How do care providers get to know him/ her? (Probe for specifics: formal procedures, requests for information from caregiver, interactions when visiting etc). How will you share your information with care providers?
4. And how do you see their knowledge of him/ her put into practice in everyday care provision?
 - What do you see?
 - What would you look for?
 - What would you notice if care was provided in an un-knowing way?

Your role in relation to formal care providers:

5. As a caregiver to your relative, do you find yourself representing him/ her to care providers – because he/ she cannot? If so,
 - What opportunities have you had to tell care providers 'stories' about your relative?
 - Do you see that as your 'job' now?
6. What would you tell care providers about how to enhance what professionals often call 'person-centred' care i.e. care that's personalized and respectful of people's individuality?