Pleasure in the Daily Lives of People Living With Advanced Dementia in a
Long-Term Care Facility: A Multiple Case Study Approach

by

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for the degree of Doctor of Philosophy

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University of Toronto

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Abstract

According to the Canadian Study of Health and Aging most of the 12,630 Canadians living with advanced dementia reside in long-term care facilities. This number is rising due to an aging population. The purpose of this study is to address an identified gap in our knowledge about what creates pleasure in people with advanced dementia, through first understanding family caregivers’ ways of eliciting and interpreting positive emotions in their relatives and then having the personal support worker (PSW) try these same approaches to see if similar responses are achieved. This study used a qualitative multiple case study design. Data collection methods included digitally recorded interviews and video-recorded observations of interactions between residents and caregivers. A case is defined as a resident with moderately to severely advanced dementia. Each case had two informants: a family member and a PSW meeting inclusion criterion. There were seven cases. The resident participants spanned a range from moderately advanced to severely advanced dementia. Data analysis used both inductive and deductive coding with sensitizing concepts of selfhood, personhood, continuity of personality and well-being.
The results of this study centred on four main themes related to the research questions about the sources and indicators of pleasure and the potential for PSWs to replicate what family members did with residents. Some sources of pleasure were lost, some were maintained and new ones developed post-illness in all of the residents. Both family members and PSWs were knowledgeable about sources and indicators of pleasure for the people with dementia they were involved with. The analysis demonstrated that for individuals with very advanced dementia, the concept of pleasure or enjoyment is not applicable. The family members of the two residents with very advanced dementia used music, touch and sweets to elicit a pleasurable response but the resident did not display indicators of pleasure in response; instead, the residents responded with grasping or other responses which require further research to understand fully. Future research should build upon these findings in order to further understand the concept of positive affect: pleasure, interest and enjoyment in people with advanced dementia of the Alzheimer type.
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CHAPTER 1: INTRODUCTION

When one’s forgetfulness becomes too much to ignore and when isolated incidents of memory lapses become frequent occurrences of disorientation and confusion, a series of events often ensues culminating in a medical diagnosis that is life altering. Thus, a person’s journey into Alzheimer’s disease (AD) begins. The ability to remember, to communicate one’s thoughts and to understand the surrounding world is slowly lost in Alzheimer’s disease and related dementias. Alzheimer’s type dementia is marked by multiple cognitive deficits in memory, one or more of language, praxis, gnosis, executive functioning causing significant impairment and decline in social or occupational functioning, [with a] gradual onset and continuing cognitive decline not due to other central nervous system or substance-induced conditions, [with] deficits not exclusively during course of delirium and not better accounted for by depression or schizophrenia (Lovestone & Gauthier, 2001, p. 2).

In the early stages of this disease, people are able to articulate their frustration and emotions related to their experiences; however, as the disease progresses, they are less able to communicate personal experiences much less what they would like to be doing – their preferences. Because AD is progressive, many elderly people live out their lives in nursing homes where the quality of their lives is now co-constructed by a world of professionals and care providers, who may or may not be expert at understanding how to care for elders with AD.

It requires expertise to understand the non-verbal gestures of the person with advanced AD. What does it require to bring pleasure to that person’s daily life? What is pleasurable to someone with advanced dementia? How does one know if the person is
indeed experiencing positive emotions? Can the person still experience positive affect amid numerous behavioural disturbances and confusion about his or her environment? To a certain extent the dialogue into sensory pleasures, pleasure inducing activities and several realms of therapy, including art therapy, music therapy, aromatherapy, cognitive therapy, and pet therapy have moved the field of research into a “therapeutic” realm. Everyday pleasure, things that family members who are most familiar with the person still do to bring about a smile, laughter or positive feelings has not been studied. An understanding of the ordinary and everyday exchanges between two people, one who has AD and the other who is determined to help that person have a good day is needed.

A smile, a laugh, a gentle touch and the sharing of a pleasant moment are all human experiences that may continue to be shared and felt well into the later stages of AD. Health care aides, who are called personal support workers (PSWs) in Ontario, work with people with dementia and often focus on maintaining the cleanliness of their bodies and the surrounding environment, as well as behavioural management and comfort of the person. This focus on the body and the external environment is understandable as it is within the educational preparation and training of these health care personnel which consists of homemaking and personal care. There are many opportunities for one to experience pleasure, joy and even fun during the course of a day while living in a nursing home; however, it is the frequency with which these moments are missed or cease to exist due to a lack of initiative or knowledge that contributes to limited quality of daily life.

Opportunities for positive affect, pleasure and interest should be integrated into everyday routines. Much of the literature related to understanding pleasant activities focuses on the knowledge family members provided about the person’s likes and dislikes,
and preferences. The focus on family members as a resource and knowledge source has led to health care providers relying on them to complete checklists of preferred activities or to create memory books with pictures. Indeed a family may have insight into responses indicative of pleasure and enjoyment including the more subtle cues attributable to idiosyncrasies. The antecedents and mediating factors resulting in the outcome of positive affect are yet to be understood. In fact, it is not known if families can identify or even articulate these cues, what comes before (antecedents) and what follows (outcomes), and the various intervening factors in order to serve as a vehicle to inform staff about how to create moments of pleasure for the person living with dementia since this has not been studied to date. There may be opportunities to find meaningful experiences and to pursue understanding of what brings joy to the individual beyond the large scale group activities of a nursing home.

Everyday life in nursing homes is still largely focused on the therapeutic and biological aspects of care. Missing is the idea that everyday interactions other than planned activities and therapeutic recreation may be uplifting and may create pleasure and joy in the residents. Creating a milieu in which these goals are equally important as are other domains of care, including skin integrity, falls prevention, behavioural management and nutrition is paramount to the preservation of dignity and personhood in the advanced stages of AD.

Purpose of the Study

The overall purpose of this study is to understand what creates pleasure in the daily lives of people with advanced dementia of the Alzheimer type living in residential long-term care settings. To accomplish this, family members’ experiences with pleasure-
inducing endeavours were explored and what happened when personal support workers (PSW) tried to replicate the strategies that families employed was examined.

Statement of the Problem

Daily life in nursing homes has been influenced by programming that emphasizes activities and a philosophy of activation with the intention that residents will not sit alone doing nothing for long periods. Despite this intention, studies have continued to show that a large percentage of a person’s day in residential settings is spent doing nothing (Burgio et al., 1994; Ice, 2002; Nolan, Grant & Nolan, 1995; Norbergh, Asplund, Rassmussen, Nordahl, & Sandman, 2001) and is devoid of social interaction outside of the routines of care (Armstrong-Esther, Browne & McAfee, 1994; McClanahan & Risley, 1975). In addition, group activities that are made available may not be meaningful to all residents and for many or even most people who have advanced cognitive impairment, the ability to participate in group activities may be lost. Thus, while activities can contribute to social interaction for those who participate in them, the challenge remains about how to maximize pleasurable interactions for the person when the ability to participate in structured (programs) and to initiate unstructured activities is severely limited.

Aside from intervention studies on the effect of pleasurable structured activities in long-term care (Buettner, 1999; Crispi & Heitner; Orsulic-Jeras, Judge & Camp, 2000; Schneider & Camp, 2002; Teri & Logsdon, 1991), a review of the literature into the daily life of those with advanced dementia who live in nursing homes revealed a paucity of information about the place of pleasure in their lives.
Although there is heterogeneity within this group, people with advanced dementia are usually unable to perform activities of daily living independently, may require assistance with eating, may be incontinent, often are immobile and at higher risk for falling if walking due to rigidity in their extremities, and may be mute or have very limited communication abilities (Reisberg, 1988). Importantly, however, there is evidence that people maintain the ability to express pleasurable affect that is observable even in the advanced stages of the disease (Albert, Cohen & Koff, 1991; Koff, Zaitchik, Montepare & Albert, 1999; Kolanowski, Litaker & Catalano, 2002; Lawton et al., 2000; Magai et al., 1996; Sherratt, Thornton, & Hatton, 2004; Tappen & Barry, 1995; Tappen & Williams, 1998; Witucki, & Twibell, 1997; Zeisel & Raia, 2000). Few opportunities for residents to feel pleasure, become engaged and interested in daily life are present in most nursing homes. Family caregivers who are knowledgeable about their relative’s preferences, aversions, and overall idiosyncrasies may serve as key informants to the care of those residents who are unable to communicate; however, the research on family caregiving has not examined the family caregiver’s role with regard to eliciting pleasure and positive affect in their relative with advanced dementia.

The quality of daily life in an institution may be increased through person-centered care. Person-centered care has influenced the field of dementia care since Tom Kitwood and the Bradford Dementia group began writing on the subject in the early 1990s. The philosophical underpinning of this study is the support of personhood (Kitwood & Bredin, 1992; Kitwood, 1997). This multidimensional philosophy of care views the resident as a pre-eminent raison d’être in long-term care. Evidence of personhood being supported includes positive affect, affectional warmth, humour,
creativity and self-expression and showing evident pleasure in these people’s lives (Kitwood & Bredin, 1992). The support of the personhood needs regular, consistent reinforcement throughout the daily lives of all individuals including those individuals with dementia. Quality of daily life is just as important for a person who has advanced dementia as any one else. It is the here-and-now – the moment – that matters to people living with dementia (Bell & McGregor, 1991; Gray & Ulman, 2004; Trabert, 1996). This person ought to have opportunities to experience pleasure through activities and interpersonal interactions as a means to having a good day (Pringle, 2003). Quality of daily life is always important. Therefore the research questions that were examined in this study pertain to positive affect, specifically pleasure in the daily lives of residents living in long-term care with moderate-to-advanced dementia.

Assumption

The over-riding assumption underpinning this study is that people with moderate-to-advanced dementia of the Alzheimer type can still enjoy life.

Research Questions

This study addressed the following research questions:

1. How do family members create pleasurable experiences for their relative who is cognitively impaired?
2. How do they draw on biographical meanings\textsuperscript{1} in creating these experiences?
3. What indicators do family members use to determine if their relative is content, interested or experiencing pleasure?
4. What happens when personal support workers try to replicate the pleasure-inducing activities/interactions that family members use with the resident?

\textsuperscript{1} In qualitative inquiry the term biographical meanings refers to the life history or the set of events making up a person’s life.
CHAPTER 2: REVIEW OF THE LITERATURE

Demographics

According to the Canadian Study of Health and Aging (CSHA, 1994), 252,600 Canadians aged 65 and older, or 8% of the 65 and over population, meet the criteria for dementia. Half of these people (51%) reside in institutions (CSHA). Although women and men develop dementia at a similar rate, there are more women living with dementia (171,400) than men (91,200) simply because women live longer than men and the prevalence of dementia rises with advanced age. A relatively small proportion of people with dementia (5.7%, 12,630) are classified in the moderate to severe end of the spectrum (CSHA). Almost all of these people live in long-term care facilities. The number of Canadians with dementia over age 65 is projected to more than double (592,000) by the year 2021 (CSHA) and that probably means a doubling of the institutionalized population. Despite the increasing number of people with dementia living in long-term care institutions, little is known about the pleasures and positive moments they may or may not experience throughout the day.

The following areas of literature were reviewed in order to fully understand the quality of daily life in nursing homes: activities in long-term care, time use in long-term care, communication of positive affect by people with advanced stage cognitive impairment, and the family’s role in long-term care facilities. All of these topics serve as background information about life in long-term care. The literature on communication in dementia differs depending on the discipline; speech language pathology and neurology differ from social work and all of these differ from nursing dealing with everyday encounters. Rather than paying attention to the various levels of conversation analysis or
the specific neurological deficits associated with speech, the focus of this review was on communication of positive affect in order to facilitate an understanding of the state of research into communication as a tool for expressing and perceiving positive affect, pleasure and interest in this population. Family interactions are central to this study, therefore examining their role in the lives of people with dementia living in a long-term care institution should serve to illuminate the state of knowledge into their contribution to their relative’s positive experiences and overall well-being.

*Activities in Long-term Care*

MEDLINE, PsycInfo, CINAHL, Sociofile (Sociological Abstracts), Cochrane and Ageline databases, the Campbell Collaboration and the library catalogue for books were searched (1990-2008) using the terms ‘dementia’ and ‘Alzheimer’s disease’ and ‘cognitive impairment’ and activity therapy, recreation therapy, art therapy, crafts, multisensory, Snoezelen, Montessori-based activities and music therapy. The articles were analyzed with respect to design, setting, intervention, measurement instruments, results of statistical analyses, findings and limitations. A set of tables that provide information about the attributes of the studies that were reviewed were created and are found in the appendices (see Appendix A).

*Activity Studies*

Activity theory proposes that if activity is substituted for lost roles as people grow older, they will experience greater life satisfaction, successful aging and well-being (Havinghurst & Albrecht, 1953). In general, activity theory has positively influenced the scope of nursing care with elderly residents including those with dementia and has contributed to effective outcomes including fewer disruptive behaviours and increased
positive affect (Pulsford, 1997). Activity theory surfaced in the early 1950s and since then several theories have challenged its assumptions including disengagement theory and continuity theory. Disengagement theory proposes that people normally disengage from the social world as they become older and retreat into life review and reminiscence, and preparation for death (Cumming & Henry, 1961). Continuity theory suggests that people continue to engage in social activities as they age at a level that is similar to their life-long patterns of activity (Atchley, 1989). Hence, activity, disengagement and continuity theories have all influenced the manner in which the aging process is understood from a social perspective. Aside from the theoretical influences on care of the elderly, there are more concrete prescriptive suggestions about approaches to care that are specific to those who are cognitively impaired.

According to the American Psychiatric Association (APA, 1997), psychosocial treatments for people with Alzheimer’s disease include: emotion-oriented, behaviour-oriented, cognition-oriented and stimulation-oriented approaches. The stimulation-oriented approaches include activity therapy, recreation therapy, art therapy and Snoezelen (APA). Snoezelen is derived from the Dutch words for ‘sniff’ and ‘doze’ and was first introduced in the 1970s as an intervention for people with learning disabilities but has been extended to the field of dementia care since the 1990s (Chung, Lai, Chung, & French, 2003). It refers to a multi-sensory stimulation of the primary senses of sight, hearing, touch, taste and smell using lighting effects, textured surfaces, meditative music and aromatherapy (Pinkney, 1997). All of these stimulation approaches are designed to be delivered in a person-centered manner. Person-centered interventions are those that are selected and delivered by clinicians “mindful of and responsive to individual and family
characteristics, such as affective states, beliefs, goals, and resources” (Lauver et al., 2002 p. 247). Many organizations have adopted a person-focused care operational model following such person-centered goals (Hurst, 1996; Mitchell, Closson, Coulis, Flint, & Gray, 2000).

Within nursing, there has been a transition from standardized nursing interventions to more theory-based person-centered interventions that include conversation (Tappen, Williams, Barry & Disesa, 2001), glider swings (Snyder et al., 2001), simple pleasures (sensorimotor intervention) (Buettner, 1999), Montessori-based activities (Dreher, 1997; Jarrott, Gozali, & Gigliotti, 2008; Orsulic-Jeras, Judge & Camp, 2000; Schneider & Camp, 2002), activity-kits (Crispi & Heitner, 2002) and Snoezelen (Baker, Dowling, Wareing, Dawson, & Assey, 1997; Moffat, Parker, Pinkney, Garside, & Freeman, 1993; Spaull, Leach & Frampton, 1998).

This literature review focuses on the stimulation-oriented approaches or activity therapies and Snoezelen as these have been most helpful for people living with advanced dementia. Twenty activity therapy studies were reviewed (Table 1). It is difficult to generalize the effectiveness of the interventions due to small sample sizes in many of the studies, and differing methodologies and control conditions. Sample sizes ranged from six to 136 residents but the most common sample size was in the range of 20-30 subjects. Among the 20 studies reviewed were three that used qualitative designs: one with a sample of 6 used phenomenological interviews to collect data, another with a sample of 23 subjects used observation to collect data, and the other one with 70 subjects used interviews. Twelve studies had quasi-experimental designs with sample sizes ranging from six to 41 residents. Five studies used an experimental design.
Measurement tools used in these studies to describe the samples included the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975), the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, Marx, & Rosenthal, 1989), and the Multidimensional Observation Scale for Elderly Subjects (Helms, Csapo, & Short, 1987). Measurement tools used to assess outcomes or effects of interventions were: the Apparent Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996), Dementia Care Mapping (Innes, 2003; Kitwood & Bredin, 1994), the Cornell Scale for Depression (Alexopoulos, Abrams, Young & Shamoian, 1988), the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1999), Clifton Assessment Procedures for the Elderly (Pattie & Gilleard, 1979), the Behaviour and Mood Disturbance Scale (Greene, Smith, Gardiner & Timbury, 1982), REHAB (Baker & Hall, 1988), Discomfort Scale for Dementias of the Alzheimer Type (DS-DAT) (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992) and the Adaptive Behaviour Scale (Nihira, Foster, Shellhaas, & Leland, 1974).

Three qualitative studies were reviewed (Kovach & Henschel, 1996; Long Foley, Sudha, Sloane & Gold, 2003; Palo-Bengtsson & Ekman, 2002). Kovach and Henschel used direct observation to collect data during music therapy, art therapy, exercise, cognitive activity and functional household activities. They found that less structured activities were associated with self-revelation in participants and spontaneity and an enthusiastic and structured activity leader was found to keep residents involved and showing positive affect and increased verbalization (Kovach & Henschel). This suggests that the qualities of the care provider may be relevant to the outcome of the activity intervention. Long Foley et al. employed qualitative interviews in a study involving 70 residents of a special care unit in order to examine the relationship between demographic
and behavioural characteristics of residents, management techniques of staff and family participation in the management of residents with severe behavioural problems. They found that family involvement was crucial to resident success. Staff employed several activities including sensory activities, walks, phoning a friend and several interpersonal approaches, e.g., redirection, one-to-one, validation, use of a calm voice, flexibility, consistent care, and diversion, to manage behavioural problems in residents (Long Foley et al.). Much of the research into the contribution of activities to dementia care has been to examine their role in the management of disruptive behaviours. Long Foley et al. identified three patterns of family interaction styles from their qualitative data: active, supportive and unsupportive. The active and supportive family interaction styles were associated with both successful and unsuccessful cases; however, staff consistently reported that these family members were more helpful than the unsupportive relatives. It is important to note that Long Foley et al.’s finding that family involvement is crucial to resident success lends support to this study’s view that family members are also key informants into creating pleasurable moments.

Palo-Bengtsson and Ekman (2002) studied six participants using phenomenological data analysis to understand the meaning of social dancing and walks in people with dementia. This study’s findings indicated that the participant’s bodily engagement during dancing created a positive physical experience when caregivers offered supportive encouragement.

Four randomized controlled trials were reviewed (Baker et al., 2003; Smallwood, Brown, Coulter, Irvine, & Copland, 2001; Spector, Orrell, Davies, & Woods, 2001; Tappen, Williams, Barry & Disesa, 2001). Two RCTs (Table 2, Appendix A) examined
cognition based therapy (Spector et al.; Tappen et al.). There were 27 participants in the Spector and colleagues’ study and the 4-phase intervention program included sensory stimulation, reminiscence, family interactions, and everyday practical issues of finding one’s way around the residential home. This 15-session program did not measure positive affect; instead, anxiety, communication, depression and family stress were outcomes (Spector et al.). The researchers concluded that 45-minute twice weekly sessions are associated with reduced depression and anxiety immediately following treatment (Spector et al.). Tappen et al. had a sample of 55 nursing home residents. The conversation intervention with exercise was aimed at the outcome of verbal communication performance in participants. This study found a decline in all groups in communication performance measured by the number of words used; however, performance in the conversation only group was better for the number of nonredundant units of information produced and conciseness.

The other two RCTs examined sensory interventions (Table 1, Appendix A). Smallwood et al. (2001) had a sample of 21 people which is very limited for an RCT design. Baker et al. had a larger sample of 136 participants in three countries in Europe. Smallwood et al. examined the relaxing effects of aromatherapy and massage, aromatherapy and conversation and massage alone on behavioural disturbances. They found that the greatest reduction in excessive motor behaviour occurred with aromatherapy and massage rather than with aromatherapy and conversation or massage only groups. Baker et al. (2003) examined the effects of eight Snoezelen sessions on behaviour, mood and cognition compared to eight activity sessions over four weeks. This study found both interventions improved behaviour and mood, increased verbal
communication and memory recall and decreased non-social behaviours in people with MMSE scores ranging from zero to 17 in both groups. Therefore, one-to-one multi-sensory stimulation was not better than activities in improving cognition, behaviour or mood (Baker et al.). Of the four RCTs reviewed in the areas of activity therapy and cognition based therapy, only the study by Baker and colleagues measured positive mood as an outcome variable.

Moffat et al. (1993) also examined the effects of the Snoezelen intervention on family caregivers and residents with dementia and found that the residents experienced increased happiness and interest along with decreased sadness, agitation, and anxiety, while family caregivers also had improved mood and decreased stress immediately following the Snoezelen intervention. Using a multiple-case design, Spaull, Leach and Frampton (1998) looked at the effects of the Snoezelen intervention on behaviours in participants and reported increased interaction, interest and active looking by participants during Snoezelen sessions along with decreased disruptive behaviours; however, these effects were not present during a 10-minute follow-up observation. Neither study clearly described the Snoezelen intervention with regard to the format of the room, procedures and principles used; therefore, it is difficult to determine whether Snoezelen was consistently applied or even whether it is feasible, available, or affordable in most long-term care settings. This limits other practitioners from using the same Snoezelen setup that was actually evaluated in the studies. In addition, it is not known which residents with dementia might benefit differently from multi-sensory stimulation or activities as there is heterogeneity in their symptoms (e.g., memory impairment, language and communication, comprehension, visual hallucinations). Information on the most effective
number of sessions, frequency and duration of these interventions has not consistently
been reported. Therefore care providers do not have enough guidance on the efficacy of
these treatments. Despite the questions arising from these studies, care providers may
take direction from findings such as Baker et al. (2003) and Spector et al. (2001) as both
studies were methodologically rigorous and had adequate sample sizes.

Hansen, Jorgensen and Ortenblad (2007) conducted a systematic review of
massage and touch for dementia. They reviewed two RCTs, one examining the use of
hand massage for immediate or short-term decrease in agitation and compared the use of
touch with verbal encouragement to eat for enhancing nutritional intake (Hansen et al.).
This review concluded that massage and touch may serve as complementary therapies for
behavioural and emotional conditions associated with dementia; however, more research
is needed for definitive evidence (Hansen et al.).

Across the 20 studies, the outcomes sought were decreased levels of agitation,
depression and negative affect, and increased positive affect, engagement, conversation
ability, relaxation and well-being. The majority of studies examined the reduction of
agitation or depressive symptoms as outcome variables and five of them concluded that
activity therapy (e.g. Simple Pleasures ©, Montessori programming, glider swing) is a
useful non-pharmacological approach for supporting people experiencing depressive
symptoms and behaviours including agitation (Jennings & Vance, 2002; Long Foley et al.
2003; Smallwood et al., 2001; Snyder et al., 2001; Spector et al., 2001). Other outcome
variables examined in the intervention studies included engagement (Althus, Engelmann
& Matthews, 2002; Kolanowski et al., 2001; Orsulic-Jeras, Schneider, & Camp, 2000;
Schneider & Camp, 2002), positive and negative affect (Kolanowski et al.; Kovach &
Henschel, 1996; Orsulic-Jeras, Judge & Camp, 2000) and well-being (Brooker & Duce, 2000). Not only have intervention studies involving activities for people with dementia demonstrated effectiveness in decreasing negative behaviours but they have also provided some evidence that activities contribute to positive affect, engagement and well-being.

Activities are often used by care providers to decrease negative behaviours and have been researched for this primary outcome. Overall eight studies measured positive affect, mood or positive responses as outcomes. There is initial evidence that Montessori based interventions, multi-sensory stimulation (e.g., Snoezelen and aromatherapy), and one-to-one planned activities (e.g., glider swing intervention; ball toss; playing cards) did result in positive affect in people with middle to late stage cognitive impairment. This evidence would be strengthened by future studies with larger samples, longitudinal designs and detailed reports about the interventions including the number of sessions, frequency and duration of specific activities. Research on the role of activities in the lives of people with Alzheimer’s disease has both theoretical and methodological difficulties including the fact that there has been a lack of emphasis on gender, ethnic and cultural factors (Marshall & Hutchinson, 2001).

Overall these studies inform care providers that multi-sensory stimulation, activities, both structured and spontaneous have the potential to create a positive mood in residents with various levels of cognitive impairment. Many of the activity studies reviewed offer care providers information about what to do including predetermined programmes of activities, activity checklists, or activity kits (Althus, Engelman & Mathews, 2002; Buettner, 1999; Kolanowski et al., 2001; Teri & Logsdon, 1991). These interventions and activities have been derived and developed through examination of the
literature in this population, been based on expert opinions (health care practitioners, other professionals), and on the researcher’s hypothesis about different interventions and their potential outcomes. The research proposed in this study will approach the question about the creation of pleasure from a different standpoint.

*Time-use in Long-term Care*

Nursing home ethnographies have offered detailed descriptions about the daily life of residents and staff alike (Diamond, 1992; Gubrium, 1993; Silverman & McAllister, 1995). In addition, the exact use of time and detailed accounts of how much time is spent doing specific activities have been documented in qualitative observational studies. Gottesman and Bourestom (1974) studied time use in nursing home residents and reported that 56% of the day is spent doing nothing. Four observational studies of how people with advanced dementia use time in long-term care were reviewed (Table 3, Appendix A). All had samples of 24 to 27 residents with advanced cognitive impairment and all were done in institutional settings. Ice (2002) carried out observations for 13 hours in a single day, while Armstrong-Esther, Browne, and McAfee (1994), Nolan, Grant and Nolan (1995), and Norbergh et al. (2001) all used a time sampling approach, observing for 10 minute or 30 minute periods intermittently over several days. Observations were done only during the day hours in all four studies. Consistently across the four studies between 51% and 71% of a person’s time was spent inactive and alone (e.g., in their room, watching television, or sitting in the hallway). While it seems likely that the environment in the care facility would impact the level of programming, activity and interaction with residents, only one author (Ice) described the environment in which observations were carried out. Even in a facility that was designed to be home-like with a
“hub” containing a nurse’s station, private or semiprivate rooms equipped with a bathroom, activity rooms, a chapel, beauty shop and library and was considered to be an optimal environment for social interaction, 65% of a person’s time was found to be inactive (Ice). These studies are limited in their usefulness because they did not examine the extent to which people were inactive and alone through choice, rather they assumed that higher levels of involvement were better and should be implemented in nursing homes. These studies reported that the majority of people’s time in long term care is spent alone and inactive. This creates opportunities to use time differently after determining whether the person wants to be more active and spend more time with others in social situations. If the residents of interest are cognitively impaired and unable to signal their preferences, then judgment must be used to determine if they would enjoy more participation and the type of participation, and guidance from family members may be useful in reaching a decision.

**Communication of Positive Affect**

The World Health Organization’s (2001) definition of conversation is “starting, sustaining, and ending an interchange of thoughts and ideas, carried out by means of spoken, written, sign or other forms of language, with one or more people one knows or who are strangers, in formal or casual settings” (as cited in Byrne & Orange, 2005, p. 191). In dementia studies, communication is defined as “the medium through which humans related to each other in meaningful ways” (Bourgeois, 2002, p. 133). This is a broadly defined area that involves several aspects of verbal, non-verbal, and gestural communication. Conceptually, communication functions to express wants and needs, exchange information, and maintain social etiquette and social
closeness (Bourgeois). As dementia progresses, marked language changes including 
incoherent verbalizations or mutism, repetitive vocal and physical behaviours and 
severely limited auditory comprehension occur (Bourgeois; Hart, 1988). Gestural 
communication (Glosser, Wiley & Barnoski, 1998) and nonverbal communication (body 
language) (Bartol, 1979) are maintained in the later stages of dementia.

Emotional expression in people during the middle to later stages of dementia of 
the Alzheimer type (DAT) has been examined. Magai et al. (1996) studied the level and 
type of affective expression in a sample of 82 nursing home residents who had a mean 
age of 84 years, were mostly women (77%) and met the Diagnostic and Statistical 
Manual of Mental Disorders criteria (DSM-III-R, 1987 as cited in Magai et al.) for DAT. 
Methods included reports from family members and health care aides, direct observations 
during family visits and coding of residents’ facial expressions (Magai et al.). They 
found that a range of emotional expression including interest, joy, anger, fear and sadness 
is preserved throughout the course of dementia. Family members reported that interest 
and joy were present and decreased only when their relatives were in late stage seven 
(Magai et al.) of the Global Deterioration Scale (GDS) which represents severe cognitive 
and functional impairment (Reisberg, Ferris, de Leon, & Crook, 1982).

Receptive and communicative emotion remains intact in dementia (Albert, Cohen 
& Koff, 1991; Danner & Friesen, 1996; Hurley, Volicer, Hanrahan, Honde & Volicer, 
(Table 4, Appendix A). Attachment is an emotion-based aspect of personality (Magai et 
al.). Three styles of attachment have been described in the literature: secure, avoidant 
and ambivalent. People who have a secure attachment style are joyful, cheerful and
likeable (Magai et al.). While emotion expression is known to be preserved in dementia, Magai and colleagues studied whether individual differences in emotional behaviours and attachment patterns are related to pre-illness patterns in people in mid- to late stage dementia. The relationship between personality prior to dementia and the pattern of emotional expression in the mid- to late stages of dementia was investigated in 27 nursing home residents, 73% of whom were female, with a mean age of 84.8 years (SD=6.6). All met the DSM-III criteria for DAT and had moderate to severe dementia according to the GDS (Magai et al., 1997). Twenty-seven family members were interviewed and they completed two questionnaires tapping premorbid personality; a current behavioural questionnaire was completed by staff. Attachment style was found to relate to the expression of positive affect in securely attached people more than those who were avoidantly attached (Magai et al.). “Pre-illness attachment style predicted the current degree of positive affect expressed by patients” (Magai et al., p. 1097). This finding lends evidence to the fact that pre-illness personality shows continuity over time even as the dementia progresses (Magai et al.). Further, the findings support the preservation of expression of positive affect in the middle to late stages of dementia.

In order to develop an observational rating scale for affect ratings of personality, indicators of depression, agitation, and external engagement were collected for 253 people with dementia residing on a special care unit (Lawton, Van Haitsma, & Klapper, 1996). Building upon work on the assessment of emotion in psychology by Ekman and Friesen (1971) and Izard (1971) as well as Lawton’s (1993) own work in the early 1990’s on affect and aging, Lawton and colleagues developed a dementia-specific assessment scale for affect for a research project in which people who had been diagnosed with
moderate to severe dementia were participants (Lawton et al.). A six-item affect rating scale (at that time named the Philadelphia Geriatric Center Affect Rating Scale) was designed to assist researchers and staff to assess positive affect (pleasure, interest, contentment) and negative affect (sadness, worry/anxiety, and anger) (Lawton et al.). Later studies eliminated contentment as an item since this was consistently difficult for staff to assess. The scale is now referred to as the Apparent Affect Rating Scale (AARS) (Lawton et al., 2000). Positive affect and the emotional experiences of happiness are reflected through the following observable signs of pleasure and/or interest:

*Signs of Pleasure:* laughing, singing, smiling, kissing, stroking gently or gently touching other, nodding, reaching out warmly to other, responding to music, crinkling of eyes, wide eyes, raised eyebrows, turning body toward something, open-arm gesture.

*Signs of Interest or “Engagement”:* participating in a task, maintaining eye contact, eyes following object or persons, responding by moving or saying something, turning body or moving toward person or object, intent gaze on object or person, or verbal response to other, body or vocal response to music, wide open eyes, gaze moves across a wide angle with head and eye movement, focus on a motor task such as dressing, eating, walking, social interaction (Lawton et al.).

Many of the contributions to the understanding of positive affect in people with moderate to severe dementia by Lawton and his colleagues, are based on establishing the validity and reliability of the AARS (Lawton et al., 1997; Lawton et al., 2000). For example, in a report on the validity of the AARS, residents’ pleasure correlated at 0.41 with certified nursing assistants’ ratings of sociability and 0.24 with family members’ rating of
extraversion (Lawton et al., 2000, p. 96). In addition they established that the AARS captures changes in a single resident over time and across differing contexts (Lawton et al., 2000).

Pleasure

Pleasure is a feeling (attitudinal pleasure) or sensation (sensory pleasure) that is caused by an “episode” that varies in both duration (period of time) and intensity (“strength or vividness”) (Feldman, 2004, p. 25). Low intensity or high intensity may not be conveyed by the person. The “intensity of an episode of pleasure is the average strength of the feeling of pleasure in that episode” (Feldman, p. 25). In a qualitative study, interviews of 19 staff members and 20 relatives of people in the middle and late stages of dementia attending a day program or residing on a Special Care Unit, Tappen and Williams (1998) reported that there seemed to be levels of emotion and gave the example of intensely positive emotions being “joyful” or “spirited” and less intense positive emotions such as “pleasant and mellow”. Therefore, the intensity of an episode of pleasure may be captured in the type of adjectives caregivers and staff report seeing.

Tappen and Williams (1998) also found that family members and staff members alike were confident in ascribing expression of emotion to people in the middle and late stages of AD. Their qualitative study looked at family and caregiver standpoints on the expression of emotion in people in the middle to later stages of AD living on a locked Alzheimer’s Special Care Unit or attending an Alzheimer’s Day Center. They interviewed 19 staff members and 20 family members (four wives, three husbands, four sons and nine daughters) who had frequent contact with their relatives (five men and 15 women) with an average age of 85 years for the nursing home residents and 81 for the
day care clients. The residents were described according to Kolb’s and Wishaw’s adaptation of Reisberg’s stages of AD: five were moderately severe, eight were severe and five were in the very severe stage of AD. Tappen and Williams conducted focused interviews lasting an average of 45 minutes with a range from 45 minutes to three hours. Respondents were asked a broad question about the way people with AD communicate their feelings and then more specific prompts about specific behaviours. For example, “what kind of gestures does s/he use?” (Tappen & Williams, p. 259). In most cases they gave specific labels to feelings expressed by residents. This study found evidence of both continuity and change in preferences. For example one resident who had enjoyed looking good, still did; others, who were described by family as outgoing and sociable, still were; whereas another resident who had always been cheerful became unhappy and a spouse who had been fearful of flying began to enjoy air travel. Family members are the repositories of this knowledge; for example, the fact that looking good was important to someone’s mother is subject to idiosyncratic detail that knowledgeable family members can provide. In this case looking good meant being well dressed; in another it may mean wearing make-up or a certain sweater and so on. It is the family member who knows the detail and meaning underlying pleasurable moments.

*Family’s Role in Quality of Life Activities*

Although not specifically about residents with dementia, Bowers (1988) identified the role of family in institutions as:

1. Telling stories which illustrated the resident’s uniqueness.
2. Demonstrating activities or directing conversations to coincide with a staff member’s appearance in the room.
3. Sharing with the staff the effect of inadequate care, particularly the resident’s distress or depression.

Family knowledge may be thought of as ‘lay knowledge’. Benner (1984) defined lay knowledge as personal knowledge, practical knowledge or “know-how”. Similarly Litwak (1981, 1985) has distinguished between the technical and non-technical tasks, specifying that non-technical tasks, which use everyday knowledge, are best performed by family members. Therefore, when the residents’ language and communicative abilities are severely impaired, family members may inform health care professionals about the resident’s personal preferences, history and personality. The literature examining families’ role in supporting the professional caregivers in long-term care for people with dementia is limited, but the evidence presented above is a starting point to further explore the families’ potential contribution to care.

There is much evidence in the literature that family members remain involved in the care of their relatives following admission to a long-term care facility (Bowers, 1988; Gutman & Killam, 1989; Linsk, et al., 1988; Moss & Kurtland, 1979; Perry, 2002). In a Canadian study of six special care units for people with dementia, Gutman and Killam interviewed 39 family members who reported being involved in activities related to meals (e.g., feeding, transporting to the dining room and encouraging eating), socializing (e.g., visiting, walks, and sitting together), grooming (e.g., shaving, washing hair, and manicures) and activities related to their relatives’ clothing (e.g., repairs, purchasing new garments, and sorting laundry). Linsk et al. found that families prefer to partake in relationship-based activities rather than personal care or structured task-oriented activities.
There is an assumption in the literature that families ought to be trained to interact with their family member with cognitive impairment (Carradice, Beail, & Shankland, 2003; Hepburn, Tornatore, Center, & Ostwald, 2001; Peacock & Forbes, 2003; Teri, 1999); therefore, interventions surrounding caregiver interactions have dominated research in the 1990s. However, there is a gap in the literature on family caregivers related to the knowledge that families possess and can offer to staff following nursing home admission of cognitively impaired relatives. A database search (CINAHL, MEDLINE, PsycInfo, Ageline, the Campbell Collaboration) using the keywords “family caregiver” and “strategies” and “dementia” or “Alzheimer’s disease” or “cognitive impairment” or “knowledge” or “management” or “skills” for the years ranging from 1990-2008 resulted in only one article on strategies used by families to care for a relative with Alzheimer’s disease (Gitlin et al., 2002).

Gitlin et al. (2002) identified a gap in research addressing the specific behavioural strategies used by families to manage the physical limitations in their relatives with Alzheimer’s disease and related disorders (ADRD). This group developed the 19-item self-report measure named the Task Management Strategy Index (TMSI) and tested the items with 202 family caregivers (Sample 1) and 255 family caregivers (Sample 2). They reported on the psychometric properties of the TMSI. TMSI scores were significantly associated with increased functional dependency, high self-efficacy and increased use of positive coping strategies in persons with ADRD. Specific behavioural strategies (e.g., introduce repetitive activities such as sweeping, raking, dusting; give short instructions; use pictures or labels to identify objects in rooms; place items in order in which they need to be used; provide rest breaks and quiet time; place your hand over the person’s hands to
guide him/her through an activity; show person what to do by demonstrating) used by families to deal with physical dependency of people with ADRD may be identified using this reliable and valid scale (Gitlin et al.). The TMSI does not identify strategies used to elicit pleasure or positive affect. The only item related to positive affect asks whether the family member keeps things that the person likes to use, look at, or touch in easy reach. The TMSI illustrates that the knowledge that families have about their relatives may be helpful in identifying specific tasks for specific purposes, such as physical dependency.

Another caregiver focused assessment is the Saskatchewan Mood Inventory (SMI) that was designed to improve the understanding of the emotional experiences of people with dementia (Burton & Crossley, 2003). Twenty-seven family members were asked to document prospectively using a semi-structured written daily log book, the type and intensity of emotion expressed and to describe the associated emotion-evoking occurrences in their relatives with dementia and their own emotional reactions over two weeks (Burton & Crossley). Descriptions in the log book were based on Lawton et al.’s (1996) affect rating scale. Positive emotions were logged less often for those with severe cognitive impairment than those with moderate levels.

Summary of the Literature Review

The ability to communicate positive affect is retained even in the later stages of dementia (Albert, Cohen & Koff, 1991; Danner & Friesen, 1996; Hurley et al., 1992; Kolanowski, Litaker & Catalano, 2002; Lawton et al., 2000; Magai et al., 1996; Tappen & Barry, 1995). Some activity-based approaches to care for people in various stages of cognitive decline resulted in decreased agitation, decreased negative affect (Baker et al., 2003; Moffat et al., 1993; Smallwood et al., 2001; Spaull et al., 1998) and positive affect
and engagement (Buettner, 1999; Kolanowski et al., 2001; Kovach & Heneschel, 1996; Long Foley et al., 2003; Orsulic-Jeras et al., 2000; Snyder et al., 2001; Spaull et al.; Teri & Logsdon, 1991). However, there is insufficient evidence to either support or discourage the use of various forms of activity therapy in working with people with dementia when the primary outcome sought is the creation of a positive mood. Multi-sensory stimulation (e.g., Snoezelen, aromatherapy) (Baker et al.; Moffat et al.; Smallwood et al.; Spector et al.; Tappen et al.) simple activities (Buettener; Teri & Logsdon) appear to work best at creating a positive mood with people with advanced dementia; however, there is no evidence of sources of pleasure experienced by groups beyond activities that occur with individuals. Programs such as simple pleasures and sensory stimulation have been created using equipment and specific activity kits (Buettener; Kolanowski; Teri & Logsdon). There is a paucity of information about other “things” that may be pleasurable. Perhaps having a certain food such as ice-cream or sitting among one’s favourite rose bushes is pleasurable for a person with severe cognitive impairment when dealing with equipment and participating in activities are not. These are examples of potentially pleasurable everyday “things” or experiences that are beyond activities.

Studies on time-use in long-term care repeatedly show that people with dementia, especially those with advanced dementia, spend the majority of their day inactive and alone (Armstrong-Esther, Browne, & McAfee, 1994; Ice, 2002; Nolan, Grant & Nolan, 1995; Norbergh et al., 2001). There is much opportunity for residents who wish to participate more with another to do so. Research has not examined the more subtle contribution that families make to the co-creation of a positive affect in their relatives.
Instead, the literature on the family’s role in long-term care highlights their assistance with basic and advanced ADLs. The development of a scale such as the TMSI (Gitlin et al., 2002) to measure management strategies used by families as well as the Saskatchewan Mood Inventory (Burton & Crossley, 2003) have both shown evidence that family members are key informants about their relative’s mood. Families are also adept at strategizing about how to simplify or manoeuvre everyday tasks to facilitate mastery and decrease frustration in their relatives in the early stages of dementia. Hence, by eliciting family expertise on the subject of pleasure, its creation will potentially increase our understanding and advance our knowledge about people with dementia.
A number of concepts are relevant to this study including relative well-being, continuity of self and retained preferences from the pre-illness period, and new interests. The philosophy of personhood frames the study. Figure 1 represents the four areas that are related to the expressed emotion of pleasure. These will each be discussed.

Figure 1: Pleasure and people living with dementia
Personhood is evident through interactions with others. Kitwood’s 1997 book was written partially as a response to the pervasive idea that people with dementia experience a profound loss of self (see for example Cohen & Eis dorfer, 1986). Based on his interactions with individuals in various stages of dementia living in the community as well as institutional settings, Kitwood argued that people with dementia are persons, that there is no loss of self and, in fact, personhood is maintained through the relationship one has with others. Personhood is defined as “the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Kitwood, p. 8). While Kitwood used the term “bestowed” to explain the relational nature of personhood, conversely it is not a characteristic that may be taken away. Rather, if “positive personhood work” does not take place in the care giving interaction then a “malignant social psychology” as evidenced by several indicators described by Kitwood et al. may occur. Examples of malignant social psychology include: infantilization, labelling, disempowerment, objectification, stigmatization, ignoring, imposition, withholding, accusation, mockery (Kitwood, 1997, p. 46). In contrast, positive personhood work consists of: recognition, negotiation, collaboration, play, celebration, relaxation and validation (Kitwood, 1997, p. 90). The underlying premise here is that people living with AD in long-term care facilities are prima facie persons in the sense of a status bestowed through relationships (Kitwood). Moreover, relationships in long-term care can be meaningful, fulfilling and person-centered (Williams & Tappen, 1999).

Thus, when one’s personhood is maintained, well-being is possible and well-being is often manifested through a positive mood or affect. Such a relational concept often lies in the domain of nursing. Nursing home ethnographies have found that many
different relationships are formed over time (Diamond, 1992; Gubrium, 1993; Silverman & McAllister, 1995). Personhood is either created or replaced by malignant social psychology in the social relationship with the person with dementia. Therefore personhood is a product of the relationship with one’s caregiver (Woods, 2001). Personhood focused care may mean paying attention to the person’s life history, past roles, culture, values and self-identity (Harrison, 1993; Normann, Asplund & Norberg, 1999; Sabat, 1998). A person’s feelings will and sensibilities are all part of his/her well-being.

Relative Well-being in Dementia

“[A] man does not consist of memory alone. He has feeling, will, sensibilities, moral being... And it is here… that you may touch him and see a profound change” (Luria, as cited in Sacks, 1985, p. 32). According to Kitwood and Bredin (1992) “a dementing condition tends to be compounded by depression, or anxiety and a sense of apathy or disencouragement” (p. 280). Therefore, relative well-being makes sense in this population as well-being is relative to the other daily conditions the person is experiencing. According to Kitwood and Bredin, the following are indicators of well-being in people with dementia:

1. The assertion of desire or will
2. The ability to experience and express a range of emotions (both ‘positive’ and ‘negative’)
3. Initiation of social contact
4. Affectional warmth
5. Social sensitivity
6. Self-respect
7. Acceptance of other dementia sufferers
8. Humour
9. Creativity and self-expression
10. Showing evident pleasure
11. Helpfulness
12. Relaxation

These indicators of well-being are most likely to occur when one is “confident, buoyant, and expansive” (Kitwood & Bredin, p. 282). Both temperament and personality result in variation of these indicators. For example, an assertive person may find it easier to convey their wishes than others (Kitwood and Bredin). These indicators can all be present in severely demented individuals (Kitwood and Bredin).

The indicators of relative well-being are to varying degrees an expression of four “global sentient states” (Kitwood & Bredin). The four states are: self-esteem, a sense of agency, social confidence and hope in the sense of basic trust. According to Kitwood (1997), people living with dementia have several psychosocial needs including:

1. comfort: “tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety” (p. 19)
2. Attachment: bonding, sense of safety; “people with dementia are constantly finding themselves in situations that are subjectively ‘strange’ and that this powerfully activates the attachment need” (Miesen, 1992, as cited in Kitwood, p. 20).
3. inclusion: having a place and a role
4. occupation: knowing about an individual’s interests, tastes and life history

5. identity: knowing detail about a person’s life history as even if the person cannot hang on to narrative identity others can; empathy for person “see them as Thou”

   (Buber as cited in Kitwood)

6. Love

Therefore personhood may be preserved when these six factors are present in the daily care of people living with dementia.

**Continuity of Self**

Some people maintain their interests and preferences for many different aspects of daily life as they age while others develop new interests and take up new lifestyles, habits or activities finding enjoyment and pleasure in these for the first time. Therefore there may be both continuity and discontinuity in aging related to the antecedents of pleasure.

Continuity is described in two ways. Atchley (1989) described continuity theory from a sociological perspective on aging. At a glance continuity theory does seem to be relevant to the entire aging population. However, upon further examination of the underlying presumptions of continuity theory, this theory is not applicable to the aging cohort with cognitive impairment because among its tenets are several specific cognitive abilities. In continuity theory “individuals are presumed to be dynamic, self-aware entities who use patterns of thought created out of a lifetime of experience to describe, analyze, evaluate, decide, act, pursue goals, and interpret input and feedback” (Atchley, 1999, p. 5). This feedback systems theory assumes that adults rely on learning throughout the lifespan to adapt. However, in individuals with cognitive impairment, adaptation has not been explained, and whether it requires memory and a high level of cognitive function is also
unknown. Therefore as expressed by Atchley, continuity does not seem applicable to
people with cognitive impairment. Several authors have described a different way of
thinking about continuity in aging and dementia – that is the continuity of self (Kitwood
& Bredin, 1992; Lyman, 1998; Post, 1995; Sabat, 2001; Sabat & Harré, 1992).

In interviewing people with dementia and uncovering several continuities related
to self, Sabat (2001) described the concept of continuity in terms of a carryover of a set of
behaviours, personality, or preference towards things from their past in people with
dementia. One may continue to experience pleasure from similar things given the
evidence of continuity in other aspects of personality and preference. Expressions of
pleasure are one aspect of behaviour so it is possible to understand non-verbal
expressions of pleasure in this population.

Sabat (2001) studied the subjectivity of experience and the impacts of a ‘hyper-
cognitive’ culture through interviewing and transcribing conversations with people in the
early to middle stages of dementia. He used an interpretative approach to describe the
experience of having Alzheimer’s disease (AD) from the person’s point of view. In
analyzing conversations, he found evidence that peoples’ selfhood was maintained in the
presence of AD. According to Sabat (2001), the manifestations of self are: Self 1 – the
self of personal identity; Self 2 – the self of mental and physical attributes; and Self 3 –
the socially presented selves, or personae. Self 3 differs from the others, in that in order to
exhibit these personae, the cooperation of others in the social world is necessary (Sabat).
Self 1 or their personal identity is evident in conversations when people with AD use
personal pronouns such as “I” or “me” (Sabat). Tappen et al. (1999) conducted qualitative
conservational analysis on a sample of 23 residents of two urban nursing homes who
were in the middle and late stages of Alzheimer’s disease and found evidence of respondents using first person indexicals frequently and coherently. This finding suggests that there is evidence of self-awareness even in the later stages of AD.

Self 2 refers to both mental and physical attributes and this is similar to the “expressed selfness” concept defined by Burgener, Shimer and Murrell (1993). In a study involving an interview of 58 caregivers (38 certified nursing assistants, 14 LPNs, and 6 RNs, with a mean of 7.6 years of experience in long-term care) and 58 elders (aged 69 to 97 years, with a mean MMSE score of 6.9) the following expressions of self in cognitively impaired elders were identified: retention of predominant skills; spirituality; despair; loneliness; connecting with others; using social skills; humour; sense of mastery; and recognition of “logical expected behaviours” (Burgener et al.). The “expressed selfness” in cognitively impaired elders indicated their ability to communicate their individuality to caregivers (Burgener et al.). Sabat (2001) also described instances of humour, loneliness, retention of dominant skills, social skills, and spirituality in the people he interviewed. Self 2, is about the resident’s attributes and each of the expressions of self found in Burgener et al.’s study represented an area toward which nursing interventions may be directed. For example, Burgener et al. suggest that individualized care plans based on past skills as well as current indicators of response patterns be integrated into the routine for each resident. Self 3 may also be integrated into such supportive care because one’s past roles, personae and socially presented selves may be a key component to participating in social life. For example, a person who held the personae of ‘homemaker’ may find that opportunities to participate in the mealtime table setting or clearing or folding napkins is meaningful as this is familiar from the past home
based work. Supporting the person’s expressions of selfness may enhance the quality of the individual’s day.

*Continuity and Premorbid Personality*

People with dementia live life moment by moment. Persons with dementia who had a pattern of secure attachment prior to dementia showed more positive affect (joy, interest) than those who were avoidantly/insecurely attached premorbidly (Magai et al.). Kolanowski, Strand and Whall (1997) also concluded that the most effective nursing interventions for dementia are those that “affirm life-long personal preferences” (p. 29). Silverman and McAllister (1995) conducted a qualitative study in a 36-bed residential Alzheimer’s facility and identified that there is continuity of specialized skills and interests (gardening, crochet, woodworking) but there are barriers that constrain role continuity including lack of availability of programming in the facility, the nature of the disease, and reactions and relationships with other residents.

Relative well-being, continuity of self and retained preferences from pre-illness and new interests all bear upon the emotion of positive affect or pleasure in people with dementia. Personhood is a relational concept. Family members’ and PSWs’ understanding about pleasure inducing activities and indicators of pleasure stem from their relationship with the resident with dementia. Family members may draw upon their life history with the resident to account for instances of pleasure that have continued from pre-illness and those that may have been newly developed. The concept of relative well-being is relevant to PSWs’ everyday care practices because the PSW may have certain activities planned and that routine may be disrupted because of the resident experiencing a mood change or intermittent illness or any number of other relative disturbances to his
or her well-being. The research questions are directed at both family members and PSWs in order to contribute to an understanding of pleasure in advanced dementia.
CHAPTER 3: METHODS AND DESIGN

Setting

The study was conducted on two of the three cognitive support units at a 472-bed university affiliated long-term care facility located in an urban area. The home for the aged is in a new facility that opened in 2000 and has an innovative non-institutional design where each floor is organized into six smaller neighbourhoods, “residentially” designed with kitchenette, common dining area and living room, and private bedrooms (79 residents per floor; 13-14 residents per neighbourhood).

Collective Case Study Research Design

This qualitative study used a collective case study approach (Stake, 1995; 2000). Case study is an appropriate research strategy to use when a “how” or “why” question is asked about a contemporary set of occurrences over which the researcher has little to no control (Yin, 2003). According to Stake (2000) “case study is not a methodological choice but a choice of what is to be studied” (p. 435). However other authors (e.g., Feagin, Orum & Sjoberg, 1991; Merriam, 1988; Yin, 2003) regard this as a methodology. According to Bromley (1986), case study is a “systematic inquiry into an event or a set of related events which aims to describe and explain the phenomenon of interest” (p. 302). For this study, case-study was viewed as a methodology. Stake goes on to identify three types of case study: intrinsic, instrumental and collective. A collective case study is described as one in which each case is used instrumentally to illustrate the issue. In this study each in-depth case analysis examined ways that families brought about pleasure with their relative and whether PSWs could replicate these strategies.
Pleasure in people with advanced dementia is the phenomenon of interest. This study’s research questions are about how family members create pleasure and how they know that they are doing so. In this study the term, case, refers to the person with dementia participating in the research. The informants to this case with regard to the phenomenon of interest include two individuals: a family member and a PSW. This study explored ways of evaluating whether the resident is experiencing pleasure during interactions with family members. Specifically, it looked at which interactions elicited pleasure. This was an initial examination into this area; therefore, it was an exploratory study. A case study approach requires an in-depth exploration of processes and individuals over a sustained period of time in order to address specific research questions.

Nursing research has built upon research methods from other social sciences such as psychology, sociology and anthropology and from the life sciences. Psychology, sociology and anthropology all offer a rich history of case study research. Generations of social science researchers and theorists have been influenced by studies on individual cases. Thus, the potential contribution of in-depth case study research towards an increased understanding of societies, cultures, processes and structures has a vast history in research to date. In fact there are three fundamental lessons that case studies can convey (Feagin, Orum, & Sjoberg, 1991). Case study:

1. allows for the study of people in natural settings,
2. provides a holistic study of complex social situations, actions and meanings, and
3. Enables the researcher to examine the continuity and change of social life over time displaying patterns of everyday life. (Feagin et al.)
Unlike the quantitative survey approach, case study research provides a way to study people, actions and events in their natural environment. In addition the participants in a case study are not disconnected from their natural surroundings, or made to partake in an artificial construction of life as with the quantitative experiment (Feagin et al.). For these reasons, a case study strategy is an appropriate one for this study.

Feagin et al. (1991) state that “case studies permit researchers to discover complex sets of decisions and to recount the effect of decisions over time” (p. 10). In relation to this study, the complexity of what family members and PSWs did to bring about a pleasurable response in the residents was understood. Using case study methodology showed how their decisions about what to do and how to do it were further understood in a holistic manner. Holistic means that the family members are not only asked to elaborate on strategies they used in the interviews; but rather, also re-enacted those strategies with their relative present thereby demonstrating this in a social setting. The use of case studies facilitated the identification of what creates pleasure in each resident and family member as well as the resident and careprovider dyad.

Case study research including data collection and analysis draws from various methodologies (Becker Hentz, 2007; Creswell, 1998) and as a researcher using this approach, I was versed in a range of qualitative methods. For example, aspects of phenomenological interviewing (Benner, Hooper-Kyriakidis & Stannard, 1999) were used as well as principles from ethnography in relation to observation, detailing fieldnotes (Emerson, Fretz & Shaw, 1995; Lofland, Snow, Anderson & Lofland, 2006) and constructivist grounded theory in relation to line-by-line coding, generating
categories and writing memos in the margins (Charmaz, 2006) as well as thematic analysis (Braun & Clarke, 2006).

A resident, a family member and a PSW form the triad of individuals making up each case study. There is evidence in the literature that family members’ expertise significantly contributes to knowledge about people who are living with severe dementia, including information on preferences, mood, and interest (Bowlby Sifton, 2000; Harrison, 1993; Hendry & Douglas, 2003). In the cases where residents cannot communicate in a manner that a health care provider can understand, families are the key informants about their relatives, owing to their knowledge of their history. Hence, family members were chosen to participate in this study. Even though this long-term care facility has several levels of regulated nursing staff: clinical nurse specialists, nurse practitioners, registered nurses (RN) and registered practical nurses (RPN); it is the unregulated staff, namely the PSWs, who were included in this study. There are more PSWs than any other type of care provider in the nursing home and they are intimately involved in the daily care of residents. For example during the eight-hour day shift the staffing includes, one RN, two RPNs and 11 PSWs for the dementia care unit (Nursing home Director [name withheld for confidentiality], personal communication, November 18, 2004). The third member of each case triad was the PSW for each resident since they are the most appropriate team members who can replicate daily pleasurable interactions.

Sampling, Sample Size and Inclusion Criteria

According to Kuzel (1999) the “unit of analysis and the overall purpose of the case study project will guide sampling decisions” (p. 38). The person with AD is the focus of analysis and the purpose of the project was to understand what creates pleasure
in the daily lives of people with advanced dementia. Both the unit of analysis and the purpose of the study guided the sampling. Instead of seeking maximum variation sampling to obtain a wide range of knowledge and views on pleasure in dementia, I selected a homogenous sampling strategy. Homogenous sampling is done when, “seeking to understand a particular group of individuals particularly well and/or control for context, with some appreciation of the unarticulated diversity yet to be explored” (Kuzel, p. 39). Purposeful sampling entails “studying information-rich cases in depth and detail” (Patton, 1999, p. 1197). Purposeful sampling was used to select residents, their family members and PSW. Purposeful criterion sampling which entails selecting all cases that meet certain criteria were used for quality control amongst the cases (Patton, 2002). A criterion-based sampling approach is appropriate in exploratory studies (Kuzel). Yin (2003) suggests for a “high degree of certainty”, five, six or more cases should be studied in a collective case design. Kuzel also recommends “five to eight sampling units” to be sufficient in a homogenous sample (p. 42). Seven case studies made up this collective case study research project.

Residents meeting the following criteria were considered for inclusion in the study: have lived in the facility for over six months, have a diagnosis of advanced dementia, have a family member who visits at least weekly, and importantly, retain the ability to express emotion. The operational definition of advanced dementia for the inclusion criteria will be Reisberg’s (1988) definition that people are likely to be unable to perform activities of daily living independently, may be incontinent, often are immobile and at higher risk for falling if walking, and may be mute or have very limited communication abilities. Recruitment focused on the abilities that the resident still has,
namely, the ability to demonstrate and express positive emotion rather than assigning a cut-off such as an MMSE score. Rhetorical devices or collegial talk was an initial barrier in recruitment where advanced dementia was better known as “total care” with staff. In other words, on a cognitive support unit, in order to identify the residents with the most advanced disease, one would have to ask for the “total care” residents, rather than sharing a list of inclusion criteria with clinical and functional indicators as this appeared complex and time consuming to staff. Part of my integrating into the setting was blending in and speaking by learning the collegial talk (Atkinson & Delamont, 2005).

Once residents who met these criteria were identified, then consideration was given to their family members who met the following criteria: are able to communicate verbally in English, visit the resident at least once per week, have demonstrated an interest in the resident’s well-being to the nursing staff, are knowledgeable about the person’s past preferences, are able to identify positive emotions expressed by the resident, and have done things in the past to bring about a positive response in the resident. One family member per resident was included. The inclusion criteria that were applied to PSWs were: employed full-time or part-time in the setting for at least three months and able to communicate verbally in English. A PSW from the unit who knows the resident but may not be their regular PSW was asked to participate for one case where the regular PSW was not willing to participate.

Participants

Seven residents, seven family members and seven PSWs made up the sample triad for this study. Family member participants were five daughters, one husband and one sister. There was one male among the six female participants ranging in age from 56 to
93 years old. Five were admitted to the nursing home from their own home, one came from a retirement home and one from a hospital. The average length of stay was 3.5 years with a range from one to six years. Four were widowed and three were married with their spouse living in the community. One had a public school education, two completed high school and four had a university education. Their previous occupations ranged from homemakers to entrepreneurs to professionals.

Five family members identified themselves in the age range of 56-65 years, one was in the age range of 46-55 years and one was over 65 years. One had a high school diploma, one had a community college diploma, one had some university education, three had a bachelor’s degree, and one had a graduate degree. Their visits to the nursing home ranged from daily to once monthly for five consecutive days (since the daughter lived in another country). The duration of a typical visit ranged from 30-60 minutes for two relatives, less than 30 minutes for one family member and more than one hour per visit for the other four family members.

Four of the PSWs identified themselves in the age range of 45-55 years, one was in the age range of 36-45 years and two were aged over 56 years. Their educational level ranged from one with a high school diploma, one with community college diplomas, one with some university education, one with an RN degree in another country, two with midwifery qualifications in another country, and one with a master’s degree in social work from another country. Three had worked at the facility for 4-10 years and four of them had over 10 years experience. All were full-time workers.
Ethical Considerations

Recruitment and Informed Consent

Research Ethics Board (REB) approval was obtained from the University of Toronto, Health Sciences II review board and from the REB of the long-term care facility with minor changes to the wording of the consent form documents. Upon receiving ethical approval for the research study, I met with the Nurse Manager and the unit RN to discuss the study and review the inclusion criteria, and to seek out potential participants (See Appendix B). The Nurse Manager was unfamiliar with the resident’s functional status so the RN and RPN were the two key informants about potential participants. Potential family participants were approached initially by the nurse manager, RN, or RPN depending on who saw them first and provided them with a brief overview of the study and asked if they were interested in getting more information about it with the possibility that they might participate (See Appendix C). They were assured by the nursing staff presenting the information that agreeing to hear more about the study would not commit them to participating. They were told that if they agreed, the researcher would meet with them at a time convenient for them, explain the study in detail, provide them with a written explanation of the study and answer any questions they might have. I spent time on the units for this reason. Sometimes family members approached me about who I was and I had informal conversations about my role there, but did not invite them to participate in the study unless the nursing staff had identified their relative as meeting the inclusion criteria. If a family member was interested in participating when I met with them, their written consent was solicited.
If some families wished to take time to consider participating they were given a copy of the information letter and consent form by the nursing staff and encouraged to call the me or my supervisor if they had further questions and were asked to contact the investigator when they had reached a decision (see Appendix D for information letter and consent forms for the appropriate decision maker, PSW and family member). In planning this study I had anticipated that written or verbal (if ability to write is impaired) informed consent would be sought from persons with dementia if they are able to understand and describe back to the researcher all of the following three points: (1) the purpose of the research; (2) the procedures involved; and (3) that they were free to refuse to participate at any time (Dubler, 1987), however, none of the participants met these criteria and therefore proxy consent was obtained for the resident from the person identified on the chart as their substitute decision maker. A substitute decision maker is an authorized third party who makes decisions for legally incompetent individuals. Even when informed consent was obtained from a substitute decision maker, the potential participant’s dissent would have precluded his or her participation in the study. There were no instances where the resident dissented to participate although one video recording session ended early because the resident was visibly tired.

Written informed consent was also sought from the PSW. Three initial information sessions were held in the conference room on the unit. The details of the study were described in an open atmosphere that facilitated discussion and questions. Since there is the potential for PSWs to interpret the videotaping of observations as surveillance that may be punitive if they were not able to replicate pleasure inducing practices, the initial information session focused on the objectives of the study and
provisions for confidentiality of the data. There were five PSWs in the first session, seven attended the second and nine attended the third session. PSWs in these groups had the opportunity to ask questions about the study. An additional five PSWs approached me individually to ask about the study as they did not attend the group information sessions. When a family member and their cognitively impaired relative agreed to participate, a PSW who worked with the resident was invited to also participate. An information package was given to the careproviders including a copy of the informed consent form so that they could review this on their own. They were reassured that their participation was entirely voluntary, that no evaluation of them as employees would occur, and that the results of the study were not connected to their employment records.

The goal of my presence on the units was to observe and familiarize myself with the routines and the residents, families and the staff while maintaining the dynamics of the neighbourhoods with the least amount of disruption. According to Ryen (2004), “trust refers to the relationship between the researcher and the participants, and to the researcher’s responsibility not to ‘spoil’ the field for others in the sense that potential research subjects become reluctant to research” (p. 234). Willingness to participate in this study was built up over time. I spent three months in the setting before successfully recruiting a family into the study. Part of the delay was about timing. I was in the setting starting in the month of November and throughout the December holiday season and into January when many families were vacationing in warmer climates. This meant that I had plenty of time to get to know the staff and the residents as I would spend the day shift sitting in the common areas meeting with potential family member participants and handing out letters of information and invitation for the project. Some of the
unwillingness to participate in the project was due to the video taping. A few family members did not feel comfortable with this aspect of the data collection and despite my assurances of the strictest confidentiality processes, were not interested in participating. This barrier seemed to decrease once one family member, resident and PSW had completed their participation in the study. Perhaps it was positive word of mouth, because after January, I successfully recruited one new resident into the study per month. Each case study was complete before the subsequent one began.

When the first case triad was identified, that case study began and recruitment for other triads was continuous as I was present on the units. I had planned to reimburse PSWs for their overtime since some PSWs would participate during their own time. This was not the case since all of the interviews and video taping occurred during their work day with their colleagues covering for them while they were participating.

Risks and Benefits

The level of risk related to participating in this study by all participants was minimal. For the residents, the potential risks are related to increased tiredness when participating in the interview or while visiting with their family member or the PSW. The time of the visitation varied from 5 minutes to 42 minutes. There was a risk of the video camera recording equipment causing the resident, family member, or PSW some anxiety, nervousness or feeling self-conscious. The camera was set up on a tripod so that it was minimally obstructive during two visits. For the remaining 12 video recording sessions, I held the camera because the tripod took up too much floor space in the resident rooms or because I was taping in a public place that involved needing to be portable with the
camera. Throughout this process, the wellbeing of the residents was monitored for signs of anxiety or distress and there were no instances where this was an issue.

There was the potential risk for family members and PSWs to feel self-conscious or nervous during the videotaping. None of the family members or PSWs requested that the videotaping be stopped. Residents were not approached for cognitive testing since staff members were able to supply all of the needed information or the information was in the resident’s medical record.

There was a risk that the family member would become emotionally upset during the interview related to the nature of the questions asking them to reminisce about their relative’s past pleasurable experiences. I encountered two family members who were teary eyed when asked to talk about the past preferences and personality of their relative. I provided a break from the digital recording of the interview and gave them an opportunity to discuss their feelings and employed empathic listening to their expressed feelings. All participants were informed that he or she could leave the study at any point without explanation and without any consequences to their current care at the facility (for the resident) or relationship with the facility (for family members) or job performance (for staff members).

The potential benefit of this research is a significant contribution to our understanding of pleasurable affect in people in the advanced stages of dementia living in long-term care facilities. The results of this project included themes about pleasure among residents with dementia and have the potential to promote their daily quality of life.
Confidentiality

For all potential participants identified by the researcher the decision to participate or not was voluntary and was kept confidential. The participant’s name was never used. In order to preserve anonymity, a random number was assigned to him/her for identification purposes. Quotations and examples of positive interactions were reported anonymously. Individual data were only accessed by the researchers. All transcribed data including interviews and field notes were kept on a secure computer and access to the computer is secured by use of specific passwords known only to the researcher. In order to preserve confidentiality of the videotapes, audiotapes and transcripts as well as filed notes and written memos, all of the data collected were kept in a locked filing cabinet at the researcher’s office at the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. Digital audio files were coded to eliminate identifying information and were stored on a password protected computer on a secure server. No information was released or printed that would disclose any personal identity of the participants. During videotape recording of observations between family members and the resident as well as between PSW and the resident, I ensured that other members of the public and staff in the surrounding environment were not videotaped. In one instance where this occurred the video segment was edited to blur the identity of these individuals. Therefore, only those who have consented to videotaping were depicted on the recording.

Data Collection

According to Yin (2003), no single source of evidence (documentation, archival records, interviews, direct observation, participant observation, and physical artefacts) has overall advantages; instead, each might be complementary to the others and they can
be used together. These case studies employed sources of evidence relevant to the study, including interviews, direct observation and documentation. In-depth semi-structured interviews were conducted with a family member and separately with their relative (see Appendix E). Interviewing each dyad together was not done because the level of questioning and dialogue relevant to the family member was beyond the conversational, perceptive and interpretive ability of the resident. All of the interviews were digitally recorded on one device and also recorded with a back-up tape recorder and then transcribed by the researcher for analysis. Interview data were regarded as topic where “the interview data collected is seen as (more or less) reflecting reality jointly constructed by the interviewee and interviewer” (Rapley, 2004, p. 16). From a constructivist paradigm, interviews are essentially interactional procedures where the interviewer and interviewee mutually note each other’s words and gestures, therefore the script is collaboratively produced (Rapley). This is in contrast to regarding the interview data as resource where there is a belief that the interviewee’s reality outside the interview is reflected in the interview (Rapley).

From a constructivist paradigm (Schwandt, 2000) family members may be seen as co-constructing meaning during their visits with their relatives with dementia. In turn, the data collection through interviews is also a co-construction between the researcher and the participants. The primary research focus is on the dynamic interaction and the creation of pleasure through relationships. Therefore, ontologically this study is relativist and epistemologically it takes on a subjectivist perspective where knowledge (about pleasure, positive affect and dementia) is socially constructed. Each case report is the researcher’s narrative, co-constituted in interviews and observations that capture the
experiences and contexts for readers who may then construct their own knowledge (Stake, 2000).

Direct observation of the interactions between the family member and the resident as well as between the PSW and the resident were collected by the researcher using video-taping. In considering what sorts of data would be relevant to fully describe each case so that this research may be completely understood and replicated by future researchers, information on affect, depression, agitation, cognitive status and stage of disease as well as social abilities were collected from each resident participant. According to Cohen-Mansfield (2000), various sources of heterogeneity in dementia including initial predisposing factors, lifelong events, and the current condition related to genetic/biologic/medical, psychosocial, and environmental sources all influence the manifestation of dementia. Therefore, cognitive, behavioural, self-maintenance and affective functioning must all be assessed to gain a thorough understanding of people with dementia (Cohen-Mansfield, 2000). Hence, residents were assessed on cognitive, behavioural, functional and affective scales in this study. Following is a description of each measurement tool.

Data Collection: Resident

1) Resident demographics

Information on the residents’ age, gender, length of residence on the unit and in the facility (perhaps on another unit) and their medical diagnoses were collected from the medical record/chart (see Appendix F).
2) Resident interview

There is evidence in the literature that people in the advanced stages of cognitive impairment retain the ability to communicate emotion and preferences (Bourgeois, 2002; Goldsmith, 1996; Mayhew, Acton, Yauk & Hopkins, 2001; Sabat, 2001; Tappen & Barry, 1995; Tappen et al. 2001). I had planned to interview each resident individually, but after meeting with their relatives I decided to informally gauge their ability to answer, simplified questions. An example of a question that was answerable in a person with an MMSE of score of six is, “what is good about life” and the response was “music” (Mayhew et al., 2001, p.109). Episodes of lucidity were found in one case study of a woman with an MMSE of 3 (Normann, Norberg & Asplund, 2002); however, this level of interviewing was not obtained in any of the residents in this study. I was able to say hello and introduce myself to five of the seven participants and got a socially appropriate response, but did not get verbal responses to my questions including “is today a good day for you?”, “what do you like to do?” and “what makes you feel happy?”. One family member suggested that her mother might become embarrassed if she was unable to answer my questions so I did not attempt to interview her, but instead shared my interview guide questions with the family member who integrated my questions into her visit. I decided to observe the interactions with staff and family members and use the data from these as indicators of positive affect.

3) Resident affect

The Apparent Affect Rating Scale (AARS) (Lawton, Van Haitsma, & Klapper, 1996) was completed for each resident at the beginning of the observation and then at the end of the observation of interaction with their family member and the PSW. The AARS
requires that one 10-minute observation be made, rating the duration of each affect state observable in that time-span (Lawton et al., 1996). The AARS is a valid and reliable tool for assessment of affect in nursing home residents with Alzheimer’s disease (Lawton et al.). The AARS is a five-item rating scale that assesses two positive affects (pleasure and interest) and three negative affects (sadness, anxiety/fear, anger) through direct observation of facial expressions, body movement and other gestures or cues that do not depend on self-report (Lawton et al., 1996). These ratings were made from watching the videotaped interactions. The first rating was made for each 10-minute videotape segment with the family member and PSW. My thesis supervisor completed the AARS for two video taped segments and her ratings were the same as mine.

4) Resident cognitive and behavioural symptoms

The Functional Assessment Stages (FAST) scale consists of 16 ordinal functional assessment stages that are identifiable in dementia of the Alzheimer’s type, which correspond to seven distinct clinical stages of progressive cognitive decline (Reisberg, 1988; Reisberg, Ferris, & Franssen, 1985). For example, observed behaviours and abilities in the mild stage will be greater than those in the moderate stage and the later severe stage. The FAST is a reliable and valid assessment tool for evaluating functional status in Alzheimer’s disease (Sclan & Reisberg, 1992). The FAST is scored primarily on the basis of information obtained from a knowledgeable informant and/or caregiver. The unit RPN and PSW were consulted to complete this assessment prior to interviewing the resident. The FAST required approximately 10 minutes to complete.
5) Resident Social Abilities

The Abilities Assessment Instrument (AAI) (Dawson, Wells & Kline, 1993) social abilities subscale was used to rate the level of retained social abilities for each resident. The AAI is reliable in terms of test-retest (Pearson’s r range .93-.99), inter-rater (Pearson’s r range .95-.99), and internal consistency evaluations (Cronbach’s alpha .90-.98) (Dawson, Wells, Reid & Sidani, 1998). It has content validity (CVI 87.3%), concurrent validity (Pearson’s r correlations ranging from .67 -.80 on the London Psychogeriatric Rating Scale, and from .76-.85 on the Functional Assessment Stages Test) and construct validity (Dawson et al.). I completed this paper and pencil test with the help of the family members and PSWs. These assessments took approximately 5 minutes to complete.

6) Resident behavioural disturbances

The Neuropsychiatric Inventory (NPI) assesses both the severity and the frequency of 12 behavioural disturbances that may be seen in people with dementia: delusions, hallucinations, agitation, dysphoria/depression, anxiety, apathy, irritability, euphoria, disinhibition, aberrant motor activity, night-time behavioural disturbances, and eating disturbances (Cummings et al., 1994; Wood et al., 2000). The NPI also assesses the distress each symptom causes the caregiver (Cummings et al.). This test takes approximately 30 minutes to administer and ratings are performed by trained health care professionals who consult with the caregivers about the person’s behavioural symptoms (Cummings et al.). According to Cummings (1997) “content validity, concurrent validity, inter-rater reliability, and test-retest reliability of the NPI are established” (p. 11). In consultation with the RN, RPN and occasionally with the geriatrician I completed the
NPI for all residents prior to interviewing their family members. A summary of the resident assessment instrument findings may be found in Appendix G.

Data Collection: Family Member

1) Family member demographics

Demographic information including age, gender, educational level, and current level of involvement with their family member was collected from each family member participant at the beginning of their individual interview with the researcher (see Appendix F).

2) Family member interview

I interviewed family members in the conference room on the unit. Interviews lasted from 15 minutes to approximately one hour. A total of 176 minutes of interview data were gathered. Family members were asked open-ended questions to address the first research question about what family members do to create pleasure in their relative who is cognitively impaired. They were asked what level of ability to express positive emotions they perceive the resident to have retained. The second research question pertaining to continuity from the residents’ past was addressed in the interview. In order to explore and understand what family members do to initiate pleasure I asked families how much carryover there was from their relative’s previous preferences; what is new; and whether they used a problem solving type of approach. The family member interviews also addressed the third research question about the indicators they used to determine if the resident is content, interested or experiencing pleasure. The interview guide was used for all interviews to remind me to give appropriate prompts when
indicated (see Appendix E). For example, if the term “indicator” of pleasure is unclear, then I sought clarification asking about “gestures” or to give an example of a smile.

Data Collection: Resident and family member

After the interviews a time was arranged for the family member to show how he or she created pleasure.

1) Resident and family member observation

Following the interview, and at a time that was convenient for the family member and suitable for the resident, the family members were asked to enact with their relative the strategies they described as bringing about pleasure. I video recorded these demonstrations. Direct non-participant observation involves watching what people are doing and listening to what they are saying. These sessions took place in the resident’s room, in the common living room area of the unit and off of the unit decided by the family member.

Data Collection: Careprovider – PSW

1) Careprovider demographics

Information regarding the careprovider’s level of education, number of years working in the institution, work status (part-time, full-time), and age were collected to describe these individuals (see Appendix F). I asked them to complete a short questionnaire containing these questions at the beginning of the one-to-one interviews.

2) Careprovider interviews

The nature of the relationship between PSW and each resident is unique therefore, PSWs were interviewed about the length of time they have worked with the resident, the nature of their relationship with that resident and whether they believe the resident still
has the ability to express pleasurable emotions. They were asked to describe their relationship using an open-ended question “tell me about your relationship with [the resident]”. Such an open-ended question allowed for the PSW to take the lead in describing what they perceive to be key elements to their relationship (Gillham, 2000). They were also asked to “describe the way in which [the resident] is able to communicate pleasure” (Tappen & Williams, 1998).

3) Careprovider Observations

The final research question: what happens when personal support workers try to replicate the pleasure-inducing activities/interactions that family members use with the resident was addressed following the interviews and observations with family members. PSWs watched the video recorded interactions that result in positive moments between residents and their family members and were asked to replicate whatever the family members do with residents to bring about pleasurable moments. These interactions were directly observed and video recorded in order to determine whether the family member’s strategy was replicated and if so, whether the resident’s response was similar or not.

While I attempted to arrange similar timing and setting, replication was not consistently done in the same setting and at the same time of day. This was due in part to the PSWs’ preferences to demonstrate their own approaches to bringing about pleasure and in some situations, to the inappropriateness of PSWs’ replicating what was essentially an intimate family interaction.
Videotaped recording

The overall purpose of this study was to explore the subtle and momentary (or perhaps lasting) emotion of pleasure when residents interact with their family members during visits. According to Bottorff (1994), videotaped recording (VTR) contributes to a more detailed observational record than traditional methods associated with direct observation. The advantages of VTR are of density and permanence (Bottorff). Morse and Pooler (2002) state:

Videotaped data presents unparalleled opportunities for understanding human behaviour…Analysis of data can be manipulated; played and replayed; sped up; slowed or paused; discussed, analyzed and reanalyzed, thus providing insights that otherwise would be unobtainable (p. 2).

The limitations are related to equipment (a single camera can only record one angle, may not pick up sound adequately), disruption of the natural setting (people may “act”), expensive equipment and the lack of context (beyond camera lens) (Bottorff).

VTR was imperative for this study to capture and review “momentary facial expressions” (Ekman, 1993, p. 389). According to Ekman “it is the morphology, the momentary configuration produced by the contraction of a particular set of facial muscles, that provides the information about whether it is anger, fear, disgust, sadness, surprise, or enjoyment” (p. 389). I did all of the video recording using a Sony® digital video camera recorder Handycam® DCR-DVD405. One video camera was used. Upon testing the equipment, the built-in microphones on the video camera were adequate so additional cordless microphones were not used. Video camera equipment was set up in a minimally distracting manner and the camera was positioned to frame the resident and family
member from the waist up if sitting or their full head-to-toe shot if standing, walking, or
dancing. Panning the wider environment or zooming in for a closer view was done for
more detail. All recording was done during the daytime in brightly lit areas so there was
adequate lighting available. I mistakenly had the camera set to “night vision” for the first
few minutes of the first video which affected the quality giving it a yellowish hue, but
this was corrected during this video and for subsequent case studies.

Video recorded segments lasted between 5.7 to 22.5 minutes. The shorter
segments were with PSWs. The videos were used to analyze expressions of positive
affect (interest, pleasure, joy) in the resident during a visit with a family member. The
videos were shown to the family members who wanted to watch them following their
interaction to verify if the segment depicted the interaction they were aiming to
demonstrate. Once the family members indicated that the recorded session adequately
shows a positive interaction, the video was used at a future meeting to teach the PSW and
their replications of these interactions were also video recorded with opportunities offered
following video recording for verification (See Appendix I).
CHAPTER 4: DATA ANALYSIS

According to Miles and Huberman (1994) anticipatory data reduction begins with the author choosing a conceptual framework, writing research questions, selecting cases and collecting data. The process of thematic analysis was used to guide the data analysis. “Thematic analysis involves the searching across a data set… to find repeated patterns of meaning” (Braun & Clarke, 2006, p. 86). The phases of thematic analysis include the following six: 1) familiarizing oneself with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, 6) producing the report (p. 87). I followed this process by first transcribing the interviews and video recorded segments and then reading and re-reading these transcripts making notes in the margins of the transcripts.

According to Miles and Huberman (1994), “Coding is analysis…Codes are tags or labels for assigning units of meaning to… information compiled during a study (p. 56). Coding is a way of breaking up the data in order to focus on a specific category (Morse & Richards, 2002). According to Morse and Richards, coding “makes resilient links between data and ideas, links that you can trace back to find where particular ideas came from and what data are coded there, to justify and account for the interpretation of the ideas” (p. 115). The data analysis was checked with my thesis supervisor after the case reports were written. The textual data from interviews and observations were stored in a Microsoft Word document organized by line numbers. I became very familiar with the transcripts as I had conducted the interviews and recorded the videos, listened to and watched the recordings and then transcribed them. Video recorded transcription was done using Transana™ software. No qualitative data management computer programs
(e.g. Nvivo, Atlas-ti) were used to manage the interview data. This decision was made after initially using a computer program and finding that it was not conducive to my seeing all of the data in one view and working with a paper copy with line numbers worked well. Tentative codes were both inductively and deductively developed based on the relevant concepts for this study and linked to the research questions. This idea of using both inductive and deductive analytic strategies has been referred to a *construction* (J. Eakin, personal communication, February 2007). Codes were not predetermined; instead, codes dealt with the following phenomena from micro to macro during field work:

1. activities and participation: brief interactions between the resident and the family member or PSW
2. meanings: the verbal and non verbal productions from participants that define and direct action
3. relationships: interrelationships amongst people

(Miles & Huberman)

Data were then initially coded using line-by-line coding where labels were given to segments of text. For example, interviews usually started off with the family member talking about where their relative lived prior to moving to the nursing home, so one of these segments was coded as “stressful move into nursing home following wandering episode”. Line-by-line coding ensured that full and equal attention was given to all parts of the transcript. Two randomly selected transcripts were given to my thesis supervisor for the entire case study including family member and PSW interviews and video recorded data for her to also do line-by-line initial coding. We arrived at similar codes
and met to discuss differences and come to a consensus. For example, my supervisor began seeing themes in the data and generated a synthesized framework after reading and re-reading the interview transcripts whereas I had focused on detailed codes. This helped to move my process along to search for themes in the data.

In analyzing the pleasurable interactions, activities and participation, meanings, relationships and settings were coded deductively with attention to the relevant concepts of personhood, relative well-being, and continuity of self as well as retained preferences from pre-illness and new interests. Peshkin (2001) outlines various lenses through which observational research may be understood to enhance the “perceptual efficacy of the researcher” (p. 238). Particular attention was given to the following areas when analyzing the videotaped segments of interaction: patterns, time, emic, positionality, themes, metaphor, irony, and silence (Peshkin). Patterns are recurrences that are generally constant under the same circumstances. Time includes duration of an event and time of day. An emic perspective refers to the perspective of those in the environment (residents, families and health care workers). An emic perspective rather than the researcher as expert stance was taken. Positionality refers to one’s role in relation to others. For example in analyzing the interactions, analysis considered whether the role of “daughter” was enacted (positioned as such) relative to the role of “parent” or whether some other roles were lived out. Metaphors, ironies (metaphor of opposites) and silences were also noted in the analysis.

Memos are notes that are written in the margins of the observation or interview transcripts or of field notes that record descriptions of the researchers’ observations of the
physical setting, the context of the meeting, ideas and impressions about parts of the interview and observation, making linkages with the literature, other data or new ideas that bear noting, categories or concepts that will be developed further (Morse & Richards, 2002; Lofland et al., 2006). There were some main overarching themes with sub themes. For example, sources of pleasure was first coded as micro, meso and macro pleasures but later changed to sources of pleasure as lost, retained and new. In trying to define levels of pleasure there was significant overlap between what I considered to be a micro pleasure, i.e., something that could be done on the unit in the moment without prior planning and meso, i.e., something that required prior planning and activities off the unit and macro, i.e., things that involved travelling outside of the nursing home. In presenting these categories at a gerontological scientific meeting, I received feedback from peers who have expertise in dementia care that the category of macro sources of pleasure seemed to be more about the family member’s needs than about the person with dementia. The discussion that followed led me to rethink my coding and to consider what the main theme was about. This was about what the family and PSW thought were sources of pleasure and things that I had thought were macro pleasures such as travel were really about lost sources of pleasure for the person. The data from case studies one and seven particularly supported this notion because their family members recounted stories of trying to take their relative on outings (i.e., a macro source of pleasure) that were, in fact, no longer feasible because of the drastic change in surroundings and unfamiliarity that led to episodes of agitation with one resident (case study seven) and anxiety with the other resident (case study one). This is one example of how the process of thematic generation became iterative moving back and forth between the data and peer debriefing in order to
arrive at the final themes. Reviewing the themes to see if they worked with the coded extracts was done by sharing a draft of the results with my supervisory committee. Their input helped to clarify meanings. For example, where the coded text did not fit with the theme I was describing, I was asked to relook at the data to clarify the themes. The members of my committee also suggested that I pay close attention to the negative cases in order to present a well rounded analysis.

Cross-case synthesis is an analytic technique that examines whether cases share similarities (Yin, 2003). For example, if a certain group of cases appear to share some similarity a “type” may emerge, or “subgroup”. Through aggregating cases relevant meanings about pleasure and people with advanced dementia living in long-term care, emerged. Naturalistic generalization is defined as “conclusions arrived at through personal engagement in life’s affairs or by vicarious experience so well constructed that the person feels as if it happened to themselves” (Stake, 1995, p. 85). These generalizations are different from propositional generalizations. Naturalistic generalizations are more private understandings that are facilitated for the reader through narrative accounts or personalistic descriptions emphasizing time, place and person (Stake). This research study will propose such generalizations in the final section.

Methodological Rigour

Several authors have suggested that the following three strategies may be used to ensure the reliability and validity of the research project: credibility/verification, reliability, and transferability (Lincoln & Guba, 1985; Morse, Barrett, Mayan, Olson & Spires, 2002; Murphy et al. 1998; Seale, 2004).
Credibility/verification

According to Lincoln and Guba (1985) credibility refers to endorsement of the research conclusions by the study participants. During the composition phase, key informants (nurses, family members and research team) reviewed a draft of the case study report. Family member participants who agreed to participate in the verification process were shown the videotaped segment at a follow-up appointment to judge the accuracy of the researcher’s interpretations. Case study is one method where problems associated with synthesized, decontextualized and abstracted data are unlikely to occur because the members are shown a summary of their single case study rather than a synthesis across all of the case studies (Morse et al., 2002, p. 7). Therefore the “transactional context”, in which the researcher tacitly directs responses and the relational context in which the interviewee presents himself or herself is maintained (Emerson & Pollner as cited in Murphy et al., 1998, p. 181). Immediately following the interviews, I offered the participants the opportunity to review the interview transcripts and no one was interested in reading over their words. These were a busy group of people and this study was already demanding several meetings for interviews and video recording so the review process was one extra time burden.

Morse et al. (2002) describe investigator responsiveness as the researcher’s skill in determining the reliability and validity of the developing study using verification strategies. During the analysis process, some of the categorization schemes which were developed early in the process were abandoned because they were poorly supported as additional case study reports were added. Themes and categories were directly linked to quotes from the transcripts as the participants are the experts on the pleasure, joy and
happiness in the lives of their relatives. My own opinions, thoughts, and emotions entered into the analysis since the interviews themselves were co-constructed between myself as the interviewer and the family members and PSWs as the interviewees. The responses that the interviewees gave to me were influenced by my behaviour as the interviewer and so the outcome of the interviews is based on the social situation not simply the attributes of the interviewee.

Reliability

Reflexivity refers to sensitivity “where researchers engage in explicit, self-aware analysis of their own role” (Finlay, 2002, p. 531). This is a difficult and ambiguous process (Finlay; Lincoln & Guba, 1985). Meaning was co-constituted between myself and the participants in my study. The family members and PSWs were presenting certain personae to me and I to them. My field notes written immediately after each interaction with participants helped me to articulate some of the unspoken dynamics and unravel some of the agendas that the interviewees brought with them. For example, it became clear to me that one family member interviewee was also concerned about other aspects of the care environment aside from my focus for the interview and she made an effort to bring these issues up towards the end of the interview. I thought about what my role was and concluded that I was a listener, that I heard her story and that she did not have any expectations of me to change the processes in place, but my listening to her was meaningful to her and to me. The connections I made with her and with other participants including PSWs and residents throughout my project helped me to write the introduction to the participants’ chapter of this thesis where I aimed to present these individuals in the way that I got to know them. One of the strongest emotions on my part
as a researcher in this setting, despite having worked in long-term care as a Clinical Nurse Specialist, was the pervasive sadness that accompanies memory dysfunction in the early stages for the residents and which lasts much longer in the eyes of family members who still see the person who once was and PSWs who fear their own fate as they age. This disease was a dreaded one and my fieldnotes after every interview reflected this.

In this research my assumptions have been examined with regard to the planning phase. The memos and fieldnotes also facilitated a reflexive analysis whereby my internal biases were illuminated throughout the research study. Debriefing sessions following interviews and observations with my thesis supervisor and regular discussions with my peers at scientific meetings and with my supervisory committee members all served to promote reflexivity.

In considering the data collection phase, the presence of the researcher on the unit is a potential source of bias because the residents, staff, and families may perform in an exemplary manner or alternately be so tense and anxious that they perform below par (Patton, 1999). This problem may be eliminated in long-term observations; however, this study was not longitudinal. Therefore, I documented problems of reactivity and attempted to measure the reactive effect in field notes and in conversations with participants (Denzin, 1978 as cited in Patton).

Inter-coder reliability was ascertained by asking my thesis supervisor to re-sort a randomly selected data set using similar coding criteria to mine. I transcribed the audio-taped interviews using a standardized transcription notation system (See Appendix H). Verbatim transcription was done whereby none of the interviewee’s responses was corrected for language or grammar. I listened to the audio-tapes and read over the
transcripts to ensure accuracy of the transcript with regard to emphasis on words, silence, pauses, and other emotional indicators evident from listening to the actual spoken words. The analysis looked at negative cases or atypical cases (e.g., cases where no positive affect is demonstrated) and examined further details of that particular case. Once the overall analysis of cases was complete, I looked for competing themes and explanations in order to promote integrity in the analysis.

During the data collection phase of this study the use of multiple sources of evidence including observation, interview, and documentation helped to illuminate converging patterns of pleasurable expressions and strategies used by families. According to Patton (1999) “the logic of triangulation is based on the premise that no single method ever adequately solves the problem of rival explanations” (p. 1192). Therefore multiple methods of data collection and analysis serve to eliminate some of the bias associated with a particular method. This study employed triangulation of methods (interview, observation and video) and triangulation of sources (resident, family member and PSW). The point behind triangulation is not to prove that different sources or approaches yield the same result; rather, it is to uncover the nuances that different methods may be sensitive to and understand the phenomenon of interest (Patton). This has helped to minimize the effects of errors related to one particular method thereby providing cross-data validity checks. According to Patton (1999), “qualitative and quantitative data can be fruitfully combined when they elucidate complementary aspects of the same phenomenon” (p. 1194). The use of the Apparent Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996) in addition to coding the interview transcripts strengthened the understanding of pleasure in this population.
An audit trail provided information for other researchers to examine the process through which this study’s researchers arrived at the conclusions (Lincoln & Guba, 1985). Alternatively plausible explanations were considered in each case analysis in order to demonstrate that all possible explanations were considered in the analysis as well as the reasons for the choice of interpretations made. Researcher capability is most important to qualitative research as it is the researcher who answers the questions (Morse, 2004). Since this research is for the purpose of my doctoral dissertation, I am a student and a novice qualitative investigator. My capability has been strengthened by reliance on members of my doctoral supervisory committee who are expert in various aspects of the research process. Regular consultation with experts in the field has ensured the credibility of the findings of this study.

Transferability

Generalization of the research findings is not the goal of qualitative case study research; instead, transferability of the findings to a similar setting is applicable (Lincoln & Guba, 1985; Seale, 1999). My providing a detailed research report facilitates this process. Lincoln and Guba state that the researcher “can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether the transfer can be contemplated as a possibility” (p. 316). Therefore the researcher herself cannot specify the external validity of the inquiry; but, researchers must make their own judgment about the relevance of one research study to their own specific context (Seale).
Limitations

There were limitations related to several aspects of this research project including sampling, data collection, and generalizability of the findings. Sampling was limited to the cognitive support units of a large long-term care facility located in an urban area. All of the participants were from a similar socioeconomic, religious and cultural background. The facility itself has a person-centred philosophy of care for residents; the environment is a newly built facility with a homelike atmosphere where residents all have a private room with their own bathroom, carpeted floors, homelike furniture and lighting which creates a warm atmosphere. This facility is not representative of many of the older homes for the aged and the extent to which the physical surroundings contributed to the findings is not known, but there may be differences if there are shared rooms and less of a homelike atmosphere. Residents all had a diagnosis of probable Alzheimer’s type dementia. It would be interesting to know about pleasure in different types of dementia such as dementia with Lewy bodies, fronto-temporal dementia and vascular dementia.

This study used the most current ideas about facial expression and emotion; however, the state of the science on facial expressions is still evolving since the pioneering research of Ekman and Friesen (1971) and Izard (1971), therefore, questions about whether there can be emotion without facial expression and how individuals may differ in their facial expressions is still evolving (Ekman, 1993). In particular, the impact of cognitive impairment on these manifestations of emotion is not known. This research relied on the opinion of family members and PSWs that the residents still had enjoyment and pleasurable moments in their everyday lives.
CHAPTER 5: INTRODUCTION TO PARTICIPANTS AND VIDEO-RECORDING DESCRIPTION

In this section, I will describe the participants of each case, that is, the resident, her or his relative and the personal support worker (PSW) who worked most closely with the resident, and provide background information about them. The purpose of introducing each of the three participants for all seven cases is to enable them to be pictured. For each resident I will provide a brief history, physical description, and a description of their retained abilities. As well, I will describe their room and a brief physical description for each family member and PSW along with information about their respective relationships with the resident. Following this, I will describe what occurred in the two videotaped sessions.

Video-recording was done for four reasons: first, to give family members an opportunity to demonstrate what they saw as pleasure; second, to identify indicators of pleasure; third, as a demonstration for the PSW of what was pleasurable for the resident from the family members’ perspectives and to point out the indicators of pleasure to the PSW that the family described to me while reviewing the recordings; and fourth, I asked family members to demonstrate a pleasurable interaction which was video-taped for the purpose of teaching the PSW what families do and to then see if the PSW could replicate the various pleasurable things that each family member demonstrated.

Some PSWs did the same thing that they saw the family member doing in the video while others chose to demonstrate something different. All family members and PSWs demonstrated a pleasurable interaction that created observable indicators of pleasure in the resident. Interestingly, PSWs and family members dressed up for their
video taping meetings. I spent several months on these units recruiting and became familiar with regular attire and appearance and noted in my field notes that there was a certain amount of pride taken in their appearance on their video taping days. The residents were also more dressed up with regard to clothing choice and hairstyle for the video days which was facilitated by family members and PSWs alike.

The following video recording process outlines the five steps that were followed for each of the seven cases (see Appendix I).

i. A video recording of the family member’s interaction with the resident was made.

ii. I watched the video recording with the individual family members who were video recorded and asked them to identify what they saw as indicators of pleasure in the resident.

iii. The video recorded segment with the family member and resident was played back for the PSW to watch during which I pointed out what the family member identified as signs of pleasure.

iv. I video recorded the PSW interacting with the resident.

v. I watched the video recorded segment with the PSW who was video recorded and asked her to point out the indicators of pleasure and to highlight any details she felt were important to understanding how to elicit pleasure.

This process will be described for each case triad. My method called for a review of the video recordings with the family members and PSWs (Steps ii. and v. above) but this usually did not happen because family members and PSWs felt that the content of their video interactions was self-explanatory. In my view, it was in fact self-explanatory.
Most of them simultaneously narrated what they were doing during the video recording. One family member declined due to time constraints. However, some PSWs and family members did agree to watch the segments and interpret their actions and for those cases their comments will be described. Please note that all of the participants have been assigned pseudonyms.

Case Study 1: Emma, her daughter Susie and her PSW, Jane

Emma is a 93 year old woman living with moderately severe Alzheimer’s disease, which is stage 7a on the FAST (Reisberg, 1988). She has lived at the long-term-care home for two years. Emma is a small woman and her weight is about right for her height. She is an attractive woman still with short hair and usually perfectly applied make-up. She dresses comfortably, always in pants with a matching sweater and wears orthopaedic neutral toned walking shoes. She has mild aphasia, but retains a few verbal communication skills such as social greetings, including saying “hello”, and “bye”. She also makes statements such as “I wanna sit down”. Emma requires full assistance with the basic activities of daily living (ADLs) including being toileted, bathed, dressed including having her hair and make-up done for her. She continues to eat on her own requiring minimal assistance with utensils as long as she receives cueing. For example, she requires cueing so that she does not end up pouring orange juice instead of milk into her cereal bowl at breakfast. She maintains the ability to walk without any assistive devices.

When I first met Emma she was walking in the hallway with her daughter Susie, arms linked. Emma greeted me with a bright smile and said “hello”. When I said, “it’s nice to see you” she replied with a “ya” and a nod, still smiling. The conversation then shifted to Susie and me with Emma watching as we walked back to her room where
Emma would spend the time with her private caregiver while Susie and I met in another meeting room for the interview.

Emma’s room is bright with a large window; furnished with the standard offerings: a single bed, bedside table and chair. However, the room did not look institutional because Susie and her sister had decorated their mother’s room to mirror Emma’s previous apartment living room. A warm and homey atmosphere was created in her room thanks to the décor including a patterned duvet on the bed, throw pillows on the chair and several frames with family photographs lining the window sill and atop the coffee table along with a few small potted plants. Her daughters also provided a television and DVD player that fit nicely in the space provided in the built-in shelving and wardrobe area. Emma is no longer able to appreciate television programs but does enjoy watching a DVD that was created for her chronicling her life story featuring family photographs.

The interview with Emma’s daughter provided rich details about her mother’s past preferences, current likes and dislikes and information about how Susie was able to know what to do during a visit. In sharing details about her mother, Susie talked about her past relationships. Emma has been married and widowed twice. Emma and her family immigrated to Canada seven years prior to her second husband’s passing away. Her country of origin was an English speaking, modern society with year round tropical climate. When her second husband passed away it triggered a series of events which alerted Susie and her husband that Emma had Alzheimer’s disease. Emma’s short-term memory loss and inability to live independently in her apartment became clear to the family. Her husband had been supporting Emma more than they knew.
Susie and her sister tried to manage care with a live-in caregiver at Emma’s apartment, but Emma was very depressed to the point where she expressed a desire to die. She became increasingly frail and unable to walk up stairs without feeling faint. It was at that point both of her daughters knew that the risk of harm was great. Susie said she was sandwiched between managing her life with her husband, children and grandchildren and her mother and her job. Susie felt that the decision to move Emma into the long-term care home is the right one for her mother but feels guilty for not being able to keep Emma at her home. Part of her guilt is attributable to her son’s strong objection to his grandmother’s institutionalization.

Upon moving to the home, Emma was upset initially by seeing elderly, frail, wheelchair bound residents with whom she could not identify. It took about three to four months for Emma to adapt to her new surroundings.

*Past Pleasures*

With regard to past pleasures, earlier in her life she had a large circle of friends and was accomplished in her job as a sales woman and small business owner along with her husband. Susie described several lost pleasures that include things that Emma did in the past but is no longer able to take part in. These lost pleasures include: reading; lawn bowling; playing cards; watching TV; engaging in conversation; and talking to friends on the telephone. Because she is no longer able to have a telephone conversation she has lost touch with all of her overseas friends whose only means of reaching her is by telephone.

*Current Pleasures*

Emma’s current pleasures were described by Susie. Having adapted to the nursing home Emma now feels happy when she can help to clear the table; can help another
resident with a meal; can fold something; is given praise; can go for a walk off the unit where she is recognized by others; can go to music programs. She also enjoys dancing; dressing up; having her picture taken; watching a DVD of her life story; visiting with her daughters; and ice-cream. Eating ice-cream is a new found pleasure for Emma who has always been conscious of her weight and never indulged in sweets. Susie has one sister who also visits Emma regularly at the nursing home. Emma especially enjoys visits from her daughters. She thanks them repeatedly for coming to see her and smiles and laughs often during their visits. She still enjoys socializing with staff members and other residents who are able to talk or even smile at her. She maintains her outgoing personality. Susie described her mother to me as a woman who took pride in her physical appearance and beauty and who still does.

Susie is a middle aged woman who looks younger than her age. She has her mother’s smile and in fact resembled the early photos of her mother which were in Emma’s room. She is married and lives nearby. She works from her home and this affords her the flexibility to be with Emma on short notice which also seems to provide added peace of mind. Although Susie’s son questioned her decision to move his grandmother into a nursing home, Susie herself was convinced this was the best place for her mother. She is a committed and loving daughter who regularly visits her mother, up to twice weekly for at least half an hour each time. Not only is her commitment to her mother evident by her attendance at the nursing home but also by the way that Susie abundantly displays her affection with hugs and holding hands. I noted that she always sat close to her.
Each time she arrived for a visit Susie would check in with the PSW about how her mother was feeling that day, how much she had eaten and would end her conversation by thanking the PSW for looking after her mother. This politeness was also extended to me each time I met Susie.

The PSW most familiar with Emma is Jane. She has worked at the nursing home for more than ten years and is considered by her peers to be one of the best PSWs on the unit based on her many years of work experience. Jane identified herself in the age bracket of over 56 years old, however, she looks much younger. She is an immigrant who has worked at the home full-time for over 10 years. Jane spoke highly of her job, stating that she enjoyed coming to work and regarded her colleagues as friends.

She saw her role as key to enabling Emma to maintain independence. She valued touch such as holding hands with Emma, patting her on the shoulder or stroking her arm as one of the things that she could do in the moments in-between ADL care to bring about pleasure in Emma. Jane described her ability to know what to do with Emma as simply relying on treating Emma the way Jane herself would want to be treated if placed in the same situation.

i. Video recording: Emma and Susie

Susie chose to bring in a tape of her mother’s favourite music which I played in a portable tape player during her visit with Emma in her room. Susie invited Emma to dance and Emma got up from her chair and began to dance with Susie. Emma smiled for the camera and danced in step with Susie. After a few minutes Susie asked Emma if she wanted to sit down. Emma said yes. The music remained playing in the background and Emma and Susie sat together on Emma’s bed. Susie asked her mother “Did you enjoy the
dance?” to which Emma replied “yes”. Susie then said “So do you know what, it's a beautiful day outside today, sunny, but very cold,” and offered to play a game of cards with her mother. Susie told me that her mother could no longer play cards, but wanted to show me what Emma would do if she had the cards placed in her hands. Susie deals the cards and Emma begins to sort through the cards she is holding in her hand. Emma could not follow the game Susie was trying to play, but did try to play. Susie praised her mother telling her:

“Do you want me to have a look? Let's see what you've got. Look you've got a good hand! … You're playing very, you're doing good, ah, this is very good, look what you've got, two nines, two jacks, two threes. I've got nothing, you want me to find a card, a good card for you?”

When Emma did not reply, Susie opted to end the card playing. Emma wanted to lie down. Susie helped her mother to get comfortable in bed and she sat in the chair next to the bed and held her mother’s hand telling her that she went to her knitting class and complimenting her mother on the previous interaction: “I was very impressed with you. You're still a good card player, and the music, do you like the music?” Emma did not reply. She seemed tired and I stopped taping shortly after she went to lie in bed.

Susie demonstrated the same type of interaction on the video as she had described to me in the interview. For example, Susie talked about her mother’s enjoyment of social activities including playing cards and visiting with her daughters. She chose to play music and dance with her mother, and did comment that it was music and dancing that currently made her mother happy. Therefore, Susie’s description of what her mother would enjoy in the interview was similar to the things she chose to demonstrate in the video recording.
ii. Video review: Susie

When reviewing the video recording with Susie, she was asked to talk about what she was doing and to point out to me the indicators of pleasure that she looked for in her mother. I took field notes on what she said. Susie pointed out Emma’s smiles and laughter as common indicators of her happy mood. Susie also pointed out that Emma was getting tired halfway through the dancing segment and that Emma was reluctant for Susie to leave as indicated by holding her hand while resting after playing cards. The indicators of pleasure with Emma that Susie pointed out were smiling, dancing along with Susie and laughing.

iii. Video playback: Jane

This video interaction between Susie and Emma was shown to PSW, Jane. While watching the video recording, Jane commented that the video portrayed Emma’s typical way of ‘showing off’ for an audience. Jane said that Emma enjoyed the company of others. After watching the video Jane and I agreed to meet in the upcoming weeks so that she could also play some music and dance with Emma.

iv. Video recording: Jane and Emma

Jane and Emma and I then met two weeks later when Jane chose to demonstrate a different pleasurable thing than card playing. The same music was played and she and Emma danced together but for a shorter time than with Susie. We met in the early afternoon and Emma had just returned from a recreational program and was tired. She commented several times during her dance with Jane that she wanted to sit down. Jane was focused on demonstrating the dancing interaction and coaxed Emma to continue dancing. I told Jane that we should stop and Emma sat down in a chair beside a table that
had a box of make-up on top. Jane told Emma she was going to do her nails and make-up. Emma smiled and showed off her polished nails to the camera. However, when Jane was applying blush to her cheeks, Emma asked her to stop and told Jane that she wanted to lie down, gesturing to her bed. Once again Jane continued with applying some lipstick telling Emma that she looks pretty. Emma then went to lie down and Jane told her that she would leave her to sleep and that she would see her tomorrow.

Jane chose not to play cards with Emma because Jane herself did not know how to play cards as she told me later on. Jane wanted to demonstrate how Emma’s face lights up and how she smiles when she is having her make-up and nails done. Jane routinely does Emma’s hair, make-up and polishes her nails. Emma enjoys dancing and that was demonstrated by both Susie and Jane. Emma wanted Susie to stay in her room while she was lying in bed but did not want Jane to stay when she lay in bed. Emma said “bye-bye” to Jane when she was in bed. Thus, Emma enjoys one-to-one company but chose for Susie, her daughter to remain at her bedside holding hands and did not want Jane to stay while she napped. The indicators of pleasure for Emma’s interaction with Susie and with Jane were the similar. Emma smiled, laughed and danced to music with Susie and with Jane. Therefore, Jane was able to replicate some of the pleasurable things that Susie demonstrated in the video-taped interaction with Emma.

v. Video review: Jane

Jane and I watched the video recording of her and Emma. As Susie had done when reviewing the video, Jane pointed out the indicators she was looking for as being smiling and laughing and “showing off” for the camera. When reviewing the video recording, Jane described how she realized that Emma was tired that day as she had just
returned from a recreational program and that usually Emma would enjoy having her
make-up applied and would not repeatedly request to ‘lie down’ and point to her bed as
she had done in the video.

Case Study 2: Mary, her daughter Patsy and her PSW, Nancy

Mary is 83 years old and has lived in the nursing home for approximately three
years. She has moderately severe Alzheimer’s disease which is stage 6b on the FAST
(Reisberg, 1988). Mary is tall and thin, but not frail in appearance. She does not wear any
makeup and has a simple hairstyle. She is still able to engage in conversations and is
socially outgoing with a sense of humour. Mary requires assistance with her basic ADLs
such as bathing and dressing. She is still able to walk unaided. Mary is married and her
husband visits every day at suppertime. They have two daughters. Mary’s husband did
not participate in the study because he felt that his daughter would be better suited to the
interview and video-taping; however, I did meet him when he viewed the video tapes
with his daughter.

When I first met Mary she was in her room with her private companion and
laughter could be heard coming from her room as I approached with her daughter. Patsy
greeted her mother with a big hug and kissed her on both cheeks saying “It’s so good to
see you Mummy. I’d like you to meet Malini. Remember I told you Malini was coming
to make a video of you today, Mummy remember?” to which Patsy replied, “Oh yes, dear,
of course I do,” and turned her attention to me saying “Hello, dear!”

Mary’s room was furnished with a bed, side table and two chairs. Her room was
very bright and sunny with family photos on the walls including a large black and white
portrait of her and her husband on their wedding day.
Patsy is tall, like her mother, and thin. She was dressed casually in jeans and a blue sweater and had a tanned natural look with little make-up and shoulder length hair cut in a bob. Patsy is close to her mother; when she visited, she greeted her with a hug and kisses on her cheek. She paid her mother many compliments and reassured her constantly telling her what was happening that day; for example, she would tell her mother which programs were offered in the afternoon and what time her dad would be coming in for a visit.

Prior to moving to the long-term care facility Mary lived at home with her husband. When her illness progressed and her husband could no longer manage alone, their family decided that Mary needed to move to a nursing home. Patsy describes Mary’s personality before moving to the home as extraverted and opinionated. Mary was always very outgoing and social and continued to value the presence of her husband, her daughters and her grandson who all visit her regularly. Mary was minimally active in the community, rather focusing on being a homemaker who spent a lot of time cooking and baking and caring for her family. She never worked outside of the home.

*Past Pleasures*

Her pleasures included reading, knitting and crocheting. Additionally, Mary liked to go out to the movies, theatres, travel and was active in aerobics.

*Current Pleasures*

While she is no longer able to read, knit, crochet, go out to the movies, travel or participate in aerobics, she does take part in recreational activities at the home depending on her mood. She participates in bingo and music programs. Mary takes pleasure in going for walks off the care unit. She enjoys socializing with other residents. She likes to
be given praise and compliments. Mary is still able to have telephone conversations once she is assisted to dial the telephone number. She recognizes the voices of her children and her husband and takes great pleasure in talking to them daily. Patsy changed her hairstyle and Mary did not seem to know it was her until Patsy’s voice was heard. Therefore, it seems that Mary relies on auditory cues more than visual cues in recognizing familiar people in her life.

According to Patsy, Mary sleeps when she is not interested in what is going on around her. When she is happy and experiencing pleasure she will show that emotion by clapping, verbalizing, giving praise to others, smiling, and “her face lights up”. Mary exhibits excitement by walking at a fast pace. Her sense of humour remains intact since she laughs appropriately during conversations. She tends to experience agitation in a variety of situations; for example, when sitting in the living room and other residents are not able to understand her or when she does not know what to do because her short-term memory loss prevents her from recalling the plan for the day that her private companion or PSW or family member have told her.

Patsy lives out of town and visits once a month for one week. During that week she spends all day with her mother at the home. Patsy manages to visit regularly despite her busy work schedule and the distance. She speaks with her mother on the telephone daily when she is away. Patsy is well-educated and articulate. She coordinates her visits with her mother’s medical appointments so she is available to take her. Mary sees a neurologist at a memory clinic where Patsy was keen to learn more about the progression of her mother’s illness and about the best treatment options available. She was a strong advocate for her mother and has spent some time educating herself about dementia. Like
many of the interviewees, Mary feared the progression of her mother’s disease and the loss of ability that is inevitable; she spoke about her mother’s current abilities in the context of what they once were and how much longer they will remain intact.

The PSW, Nancy, has known Mary since she moved into the nursing home and describes her relationship with Mary as “very good”. Nancy has worked at the home full-time for over five years. She is very soft-spoken and knows all the residents on the unit. In her interview with me, Nancy told me that she believed that Mary still had many abilities and needed other residents around her with whom she could interact. Mary was “higher functioning” than the majority of residents who lived there. Nancy noted that this was difficult and a point of frustration for Mary. However, Mary had a private companion who often filled her need for someone to chat with if Nancy or her colleagues were busy attending to the care of other residents. Nancy was openly affectionate with Mary, often holding her hand or paying her compliments for helping her to have a good work day.

Nancy believes pleasure is still possible for residents in the nursing home including Mary. She believed that the key to dealing with agitation in Mary is to approach her the right way; for example, with morning care, taking a calm and patient approach works well and the care moves along smoothly with Mary even thanking Nancy for her help. Nancy also said that Mary enjoys being praised for helping, for looking nice, and for doing things. She shared some specific compliments that Mary enjoys receiving: “I like your smile”, “I’m happy now that you’re here”. According to Nancy knowing the resident and that small things can frustrate her, sometimes it helps to just sit with her and calm her down or to take away too many stimulating things or to simplify tasks such as dressing and eating meals.
i. Video recording: Mary and Patsy

The pleasurable interaction Patsy chose to do for the video was to go for a walk off the unit with Mary. Since Patsy lives out of town and Mary had not seen her for a couple of weeks, Mary was happy to see her daughter and greeted her with a warm hug and kiss. I began filming as Patsy and Mary walked down the corridor outside Mary’s room towards the elevators arms linked. Mary retains more abilities than all of the other residents and is still able to engage in conversation. For example, when Patsy was telling Mary about all of the people they might meet in the lobby area, Mary replied by saying “It's always nice to have company.”

Mary and Patsy sat beside each other on a bench and Patsy led the conversation. They both smiled and held hands. At one point in the conversation Patsy was recounting all of the visitors that came to see Mary throughout that week and Mary said “I'm very lucky, I've got very nice, very nice people looking after me and visiting me, I can't complain about anything.” Mary expressed her gratitude for her daughter’s visit and to have the pleasure of other family members’ company. After talking about all of the people that had visited her, Patsy began to tell Mary about all of the activities that were happening in the home that day. Here is a typical verbal exchange; when Mary encounters some word finding difficulty, Patsy, helps her out:

Mary: “And I'm going to have a lovely afternoon and evening. “
Patsy: “Good and why is that?”
Mary: “Because you're here, and this lovely lady is taking, she's taking…”
Patsy: “She's taking your picture huh?”
Mary: “Oh, isn't that nice? Hello.”
Mary made certain to express her appreciation for the time and attention she was getting from both Patsy and me as the camera person/photographer. Mary repeatedly used the adjectives wonderful, good and lovely when describing the things she enjoyed doing.

Mary and Patsy took a walk to see if any of Mary’s friends were nearby to chat with. Mary saw one of her friends sitting with her caregiver and the two friends began chatting. When her friend asked her how she was doing, Mary replied with:

“Thank God my family is good. Can't complain, my husband is good and my daughters are good and… my grandson, Ah, he's a joy. Very nice child.” Mary and her friend also began singing on Patsy’s suggestion that they sing together. The visit wrapped up with saying good-bye to her friend and returning to the unit with Patsy.

**ii. Video review: Patsy**

Patsy and her father, Mary’s husband, reviewed the video recording in the conference room at the nursing home. Mary’s husband knew about my study and suggested that Patsy was a better candidate to participate but he was interested in seeing the video recording. Patsy watched the video and made comments about how her mother had changed. She commented to her father and me that soon her mother would not be able to have a conversation. She laughed at her mother’s sense of humour and did not comment much on what was happening in the video as Mary maintained many verbal and social abilities. Her video was self-explanatory and did not require much interpretation from her family members.
iii. Video playback: Nancy

The video-taped interaction was showed to the PSW, Nancy. Nancy watched the video recording with Patsy and Mary and told me that she will do something very similar with Mary since Mary enjoys going for walks off the care unit and socializing with others.

iv. Video recording: Mary and Nancy

Later that week, I met with Nancy and Mary to video-tape an interaction. Nancy did the same thing that Patsy did by taking Mary off the unit down to the main lobby to sit and chat. They sat on the same bench that Patsy and Mary had chosen during their visit. The conversation was guided by Nancy. Once again, Mary enjoyed having me take her picture (she referred to the camcorder as a camera) even posing with Nancy for the camera, smiling. Nancy talked to Mary about her children and engaged in reminiscing with the story of how Mary met her husband. It was a story that Nancy had been familiar with and she chose to talk with Mary about how she and her husband met, fell in love and got married. Mary smiled and nodded as Nancy told the story back to her. Nancy also talked to her about Mary’s children and grandson. She knew that Mary enjoyed talking about her family.


Case Study 3: Anne, her daughter Emily and her PSW, Betty

Anne is 88 years old and has lived at the nursing home for three years. Anne has very severe cognitive decline which is stage 7e on the FAST (Reisberg, 1988). She has shoulder length silvery grey hair that was combed with a part and two clips holding back the sides. While she maintains the ability to swallow when fed, all of her verbal abilities are lost and she rarely opens her eyes. She no longer makes any sounds. She is in a
wheelchair and requires full assistance with her ADLs including being bathed, fed, dressed and toileted.

Before relocating to the nursing home three years ago, Anne lived in a condominium with her husband. She is now a widow; her husband passed away two years ago. They were married for 60 years and have two daughters. They immigrated to Ontario from the United States of America early in their marriage. Anne stayed at home and raised their children. While alive, he was very dedicated to her, visiting every day for the first six months of Anne’s move into the home.

Emily describes Anne’s past personality as outgoing with a great sense of humour. Emily explained the decision to move Anne into the nursing home was controversial because there was no consensus in the family or from her mother. Anne had a difficult transition to the nursing home and fell a few times after moving. Anne’s declining memory including not recognizing her husband became emotionally difficult for the family. One of the things Emily helped out with while Anne was still living at home was meals. Her mother liked to be brought her meals usually baked salmon and baked sweet potato and ice-cream. Emily would bring Anne chocolate cake occasionally.

Past Pleasures

Anne and her husband traveled south each winter for over 30 years. They both shared a love for musicals and attending the theatre with their friends. Emily considered her mother to be her best friend. Anne had many long standing friendships and was adored by her girlfriends. She was a homemaker who was very athletic. Her past likes include playing bridge, Broadway musicals, dining out, long walks, golf and swimming.
Emily hired a private companion once Anne moved into the nursing home to assist with feeding Anne her meals in her room. This was needed because one of the challenges of living in collective setting became sharing a table with another resident who was disruptive to Anne’s mealtime. Anne also requires extra time to be fed because of her dysphagia.

**Current Pleasures**

Anne is no longer able to partake in those activities where there were sources of pleasure carried over from her younger days and current pleasures seem to be limited to three sources: touch (stroking her arm, holding her hand), taste (chocolate ice-cream, applesauce) and music (Broadway musicals). She never liked sweets earlier in her life aside from chocolate cake on her birthday.

When I met Anne, she was sitting in her wheelchair in her room in front of the television which was turned on and had a musical playing. Her room is decorated with a few photographs on her bedside table and one plant on the window sill. Anne was wearing a red sweater which seemed to bring a red glow to her cheeks. Her eyes remained closed with her head downward while Emily, her daughter, introduced me. I moved closer and touched her hand after Emily told Anne that I was in the room. I did not get any response from Anne.

Emily is a dedicated daughter. She is the opposite in appearance to her rather slim and tall mother. She identified herself in the age range of 56-65 but looks closer to the younger end of the range. She visits her mother two to five times weekly and spends over an hour each time. She speaks to her mother in a caring and gentle tone. Many of her phrases are reassuring. She has mastered the task of carrying on a one-way conversation
with her mother. Since Anne no longer speaks nor does she communicate with any sound, Emily described the things she looked for to know how her mother may be feeling at any moment. She is well versed in dementia and often teaches staff how to care for her mother. Feeding Anne requires an hour or more and Emily usually helps out with meals. She has a strong sense of filial piety and loves her mother dearly.

Betty has worked as a PSW in the home for over seven years. She identified herself in the age range of 46-55 years. Her broad smile is the first thing I noticed when meeting her. She is energetic and enthusiastic about her work. Betty did not always work in long-term care and since moving into this field from acute care, she feels that it is much more rewarding because of the length of time she has to get to know the residents and their families. She described that it is emotionally difficult to see residents lose abilities.

Betty has worked with Anne since she moved into the home. She has seen Anne lose abilities and become quite frail. She remains optimistic that Anne still enjoys meals and that with patience, Anne will open her eyes and become somewhat responsive to the feeding interaction between them. She still sees some joyful emotion in Anne during breakfast. She communicates with Anne and gives her a complete overview of her day every day with the belief that Anne still understands her. Throughout her work day, Betty tries to acknowledge Anne by patting her on the shoulder or holding her hand just to let Anne know that “she is not alone”. Anne mumbles a lot and although she is not able to decipher it, Betty believes these are meaningful attempts of communication from Anne. For example, when Betty asks “do you like your food”, Anne replies with “mmmmmm”. This is indicative to Betty that Anne takes pleasure in mealtime and enjoys the food.
i. Video recording: Anne and Emily

I videotaped Emily visiting her mother Anne. Anne was in her room sitting in her wheelchair. Emily thought the most pleasurable thing for her mother would be to play a Broadway musical on the TV and to feed her mother ice-cream or applesauce as Anne preferred sweets. Throughout the video taping Anne remained silent. Emily talked non-stop to her mother. The following is an example of Emily’s verbal interaction with Anne:

“Do you like the movie? Hmmmm? Oh you're cold. Are you cold that you're holding? (touches her mother’s hands). No, you're not cold. Oh, this is a good song isn't it? (humming along with song)... Are you sleeping? Are you having a sleep? Mummy, do you like this song? Let's see, we'll make it a little louder for you. Oh, this is a good song isn't it? Do you want to have some juice? Are you tired? Are you sleeping?”

Emily asked somewhat rhetorical questions since Anne was not responding in any way verbal or non-verbally to her questions. Later when Emily and I watched the replay of the video tape she told me that she thought it was important to always communicate with her mother. She made certain to always tell her what was happening in her room and what she was doing. When she fed her mother the applesauce, Emily said:

“Apple sauce, do you like it? Mom, ma ma. Do you like this apple sauce? Sweetheart, let's see, let's see if it's any good. What do you think? Good?” She told me she did not expect an answer from her mother, but that Anne might not open her mouth for the next spoonful therefore communicating that she did not want any more. This was not the case as Anne continued to accept the applesauce and finished whatever Emily had brought to feed her. Emily’s approach to feeding her mother was very specific. She first made sure that there was a napkin on her table tray and as she gave Anne a spoonful of applesauce she stroked Anne’s forearm and talked to her asking if it tasted good and if it was a good brand and if she should buy it again.
ii. Video review: Emily

Emily considers herself expert in her mother’s subtle expressions of pleasure. When we watched the video tape together, Emily pointed out a smile in Anne. I had to pause and rewind this segment several times before I could also see the subtle upward turn of her facial expression that Emily relied on to know whether Anne was happy with the applesauce or whatever other pleasurable thing was happening. This signal was not seen in the PSW video nor did the PSW recognize it when I showed her the videotape of Emily and Anne.

iii. Video playback: Betty

Betty, Anne’s PSW watched the video with Anne and Emily. The video recording with Anne was one of the longest video recordings of all the case studies lasting about 45 minutes. Betty reviewed part of the video and I fast forwarded the video to the point where Emily pointed out Anne’s smile. Betty did not see the subtle smile at first, but after replaying this a few times, she agreed that there might be a very slight change in Anne’s facial expression. Betty felt that Anne’s facial expressions were not noticeable to her.

Betty was more concerned with Anne’s verbalizations and eye contact as expressions of interest and sometimes pleasure.

iv. Video recording: Anne and Betty

Betty invited me to return to videotape her feeding Anne breakfast. Betty thought it was too early in the day to play the musical on the TV, so this aspect of the interaction differed from Emily’s approach using both music and food to elicit pleasure in Anne. Betty also had a very specific approach to feeding Anne. First, she introduced herself, telling Anne her name and that she would be looking after her that day. Betty then opened
all of the items on the food tray and then she added milk to the cereal and respectfully placed a towel bib over Anne’s clothing. Betty had combed Anne’s hair to make her ready for the camera. Betty’s tone of voice was similar to Emily’s when talking to Anne. Both demonstrated respect for Anne by telling her what was to be expected. For example:

“Hi, good morning star shine… Hi Anne… Anne… Mrs….. Hi Miss. Beautiful… Hello Anne. Alright, try some porridge sweetie. Good okay swallow it down. Is it good? Hmm? Here open your mouth. I have some more. Good girl. Okay, swallow it down dear. Yes. I'm here with you. Good. Can you open your eyes sweetie? Hmm?”

The terms “good girl” and “sweetie” were also used by Emily, Anne’s daughter in her video. Betty asked Anne repeatedly to open her eyes. Eventually Anne did open her eyes for fewer than five seconds. Betty continued to feed Anne her breakfast and Anne made some grunting sounds. Anne also took her bib and wiped the corner of her mouth after a spoonful of breakfast. Betty praised and encouraged such actions from Anne. Betty also asked Anne whether she had slept well, told her what the weather was like outside and chatted with her throughout the meal.

v. Video review: Betty

In reviewing the video recording with me, Betty pointed out Anne’s limited ability to swallow. She mentioned that breakfast is the only meal that she feeds Anne and that it is highly time consuming compared to the other residents for whom she provides assistance with ADLs. She told me that Anne has a private companion who feeds Anne her lunch and dinner in her room. Betty became animated and told me to look and see how Anne is opening her eyes at the point in the video where Anne did open her eyes. I asked her what this indicated to her. She felt that by opening her eyes, Anne was indicating that she understands what Betty is telling her. Betty also told me that she
thinks it is important to always talk to Anne as if she was awake and alert. Betty thought the video captured how Anne expressed pleasure during mealtime with her eyes opening occasionally and her participating in the meal by reaching for her bib to wipe food away from the corner of her mouth.

Case Study 4: Isa her husband George, and her PSW, Alice

Isa is 71 years old and has very severe dementia which is stage 7d on the FAST (Reisberg, 1988). She has lived in the nursing home for four years. She has lost the ability to speak, is in a wheelchair and requires full assistance with her ADLs including bathing, toileting, dressing and feeding. Isa is tall and thin. She has short greying hair styled with a side part. She wore a single strand of pearls around her neck and very little make up aside from some pale pink lipstick. Her eyes remained closed throughout my time with her.

On the day I met Isa, she was in her room, sitting in her wheelchair facing the window. Her room was neat and tidy. There was no television but a radio tuned to a classical music station was on her bedside table along with a lamp. Several art gallery prints were framed and hung on three of the walls. Her husband George told me that Isa was an art teacher and so he had brought these pieces to put up on the walls to remind her of something that she enjoyed.

She moved to the nursing home from her home where she and her husband lived together. George is a tall man, somewhat over 65 years with grey hair and glasses. He told me that he is in the early stages of cognitive impairment and asked for my patience with his interview. He came across as a sad man. He seemed to miss Isa being home with him. He realized that he could not care for her at home, but reminisced during our
interview about their past. He did not provide details – either he was not able to or not used to; he mainly answered the questions I asked with little elaboration. He did recount, however, the story of how Isa was admitted to the home and how she was once able to walk and talk, so his visits used to be more interactive. Now he spends more than one hour, and usually comes to see Isa every day. While he expressed difficulty with knowing what Isa needs, he is convinced his visits are meaningful to her.

Isa moved to the nursing home after she was no longer able to manage her household. She and her husband George lived alone in their home and George told me that he wanted his wife to say at home but that eventually he could not cope. They have two children and grandchildren who visit infrequently now because they cannot talk to each other. They believe that Isa does not understand them.

*Past Pleasures*

Prior to moving, Isa enjoyed walks in the park and when George read to her. She also enjoyed going to the theatre to watch plays. George reported that Isa had a joyful, happy, and pleasant personality.

*Current Pleasures*

Isa responds to George by holding his hand. George believes this is a sign that Isa recognizes him. Isa currently takes pleasure in mealtime. When George visits he takes Isa to some programs including music concerts and singing groups. George smiles and talks to her even though he feels that she does not understand. According to George, Isa sometimes says a word. He talks to her about the children, the family, about who came to see her.
Alice is the PSW who has worked with Isa since she moved into the nursing home. Alice placed herself in the 46-55 years old age range. She has worked at the nursing home for 17 years full-time. She is an immigrant who was trained as a midwife in her native country. Alice had a negative view of Isa’s ability to experience pleasure. In fact, she told me that Isa was “totally gone”. Later in the interview when I asked her about any possible simple instances of joy, she was able to recall that Isa liked to eat. There was somewhat of a disconnection between what Alice stated in her interview with me regarding Isa’s ability to experience pleasure because while she states that Isa is “totally gone” placing emphasis on lost eye contact from Isa, she still continued to speak with Isa and feed her in a very compassionate and caring manner. She also recounted that Isa responds to hand holding by grasping tightly. She has also seen Isa smile intermittently but could not recall if there was a particular thing happening when Isa smiled. Alice believed that because Isa kept her eyes closed much of the day that Isa was no longer experiencing pleasurable moments.

i. Video recording: Isa and George

George did not feel that he was the best person to demonstrate something that was pleasurable with his wife, Isa. He was concerned about not being able to do what I wanted. I encouraged him to show me what a typical visit would be like and to point out the tight hand grasping that he described to me in the interview. George agreed to be videotaped and on the day of the taping he sat beside Isa in a chair in her room. There was a dessert pudding on the table next to him that the private companion had left for him to feed Isa after lunch in the dining room. He greeted Isa with a hug and kiss on the cheek. He told her he was happy to see her and that he has a nice dessert to feed her. Isa’s
demeanour was relaxed as she sat in her wheelchair. She had a pleasant expression on her face. He began feeding her and encouraging her to swallow each spoonful. This is an example of George’s encouraging words to Isa: “Yes, you like it? Is it nice? Is it sweet? This is a good meal... That's a girl, good, good, good. That's right, open your mouth dear... Do you like it? I think you do.” Throughout the time he was feeding Isa, she made several verbal grunts and groans. This is the extent of her verbalization. Her facial expression was relaxed. She moved her head forward to accept each spoonful of the pudding appearing to want more to eat. This indicated that she engaged in the meal experience with her husband. He chatted with her about the weather and also told her that she was doing well with her eating. He rarely fed her since her private caregiver or the PSW did this, but occasionally he did feed her dessert. George held Isa’s hand and pointed out to me how tightly she was gripping his hand. He believed this was a positive indicator of pleasure in her.

ii. Video review: George – declined.

iii. Video playback: Alice

I showed the tape with George feeding Isa to the PSW, Alice. While watching the playback of George and Isa, Alice nodded and commented that Isa behaves similarly with her. Alice and I met a week later for her video recording session with Isa.

iv. Video recording: Alice and Isa

Alice also fed Isa in her room sitting on a chair next to her. Alice was pessimistic about whether Isa could still experience positive affect. Alice thought that Isa’s daily life in the home was not joyful or pleasurable because of the extent of her illness. However, she did believe that Isa still liked eating, because Alice noticed that Isa always ate
everything that was presented to her at every meal. Alice thought that because Isa rarely opened her eyes, no longer spoke and was confined to a wheelchair that there were limited opportunities to experience pleasure. However, Alice, upon seeing the tape with George agreed to also feed Isa and show me how she interacts with Isa.

Alice fed Isa a custard dessert after lunch. Isa responded to Alice much like she did to George. She was receptive to every spoonful by bending her head forward in anticipation of the spoon touching her lips. Alice talked to Isa about the weather and even offered to turn Isa’s wheelchair towards the window to see what a cold and windy winter’s day it was outside. Alice demonstrated a respectful approach to Isa. She talked to her about the day, about the weather and did not treat her in an undignified manner even though in the interview she expressed a negative view about Isa’s quality of life and ability to still experience pleasure.

v. Video review: Alice

In reviewing the video with Alice, she talked about Isa’s grasp. Although Isa did not grasp Alice’s hand in the video segment, Alice did tell me in the interview that Isa has a strong grip and does hold on during care procedures. Alice interpreted this as Isa not wanting to fall or feeling insecure in some way. This was a different interpretation of Isa’s tightly grasping than George’s interpretation. George thought this was an expression of commitment and love.

Case Study 5: Marjie, her sister Liz and her PSW, Theresa

Marjie, the youngest resident in my study is only 56 years old and has early onset dementia of the Alzheimer type. She is currently in the middle stage of the disease which is stage 7b on the FAST (Reisberg, 1988). Her verbal abilities are limited to fewer than
10 words. She usually responded with “yes” or “no” and laughed or smiled when the person talking to her did so. According to Liz, Marjie maintains a sense of humour and laughs still. She maintained the ability to walk, but required a wheelchair for long distances. She looks too young to be in a nursing home setting resembling a staff member rather than a resident. She has curly short, black hair and wears glasses. Her neck was crooked downward some of the time. She has gained weight since she moved into the nursing home and as a result was put on a reduced calorie diet. She has moderate depression and walks the hallways repeatedly until she is tired at which point she sits on the sofa in the living room area of the home. She does not like to sit in her room alone and had previously enjoyed walking, so perhaps her choosing to walk now was her expression of selfhood.

When I met Marjie she was sitting on the sofa in the living room of the nursing home. She was dressed casually and comfortably in a t-shirt and track pants with running shoes, likely to facilitate her frequent walking on the unit. She raised her eyes to look at me when I said “Hello Marjie, my name is Malini”. She had a pleasant expression on her face.

Marjie is married and her husband visits her irregularly. I never met him during my time at the home, perhaps because he came later in the evenings after I was gone for the day. Marjie’s room was sparsely decorated with one picture frame on the wall with several small family photos in it. There was a lamp on the bedside table and a radio. She also had several soft toys/teddy bears lying on the two chairs in her room. There were some trinkets such as a vase and a musical flower ornament on the window sill.
Marjie’s sister, Liz participated in the study. She checked the 56-65 age range to reflect her age group. She’s shorter and heavier set than Marjie and has short straight reddish brown hair. The two sisters resemble each other. She and Marjie’s husband are not in communication with each other. Liz told me that Marjie was university educated and had a successful marketing job. Liz describes Marjie’s personality as quiet, but someone with a great sense of humour and a quick wit. Growing up the two sisters got along well and shared a strong friendship. Before Marjie moved into the nursing home, she lived only a block away from her sister. Marjie’s mother is still alive but lives out of town so rarely comes into visit her. Liz spends time during her twice weekly visits updating Marjie on how everyone in the family is doing. She usually spends up to an hour visiting Marjie.

Past Pleasures

Prior to moving to the nursing home, Margie lived at home with her husband but attended a day program at the nursing home. Margie had many sources of enjoyment in her life including: gardening; walking; caring for her dog; going to the theatre with her husband; playing sports; skiing; sailing in the summertime; reading; listening to music; and eating fresh fruit, especially peaches.

Current Pleasures

Liz believes that Marjie’s current pleasures include chocolate cookies; ice-cream; sweets; being off the unit; attending concerts; people watching with her companion; short walks; going to see the garden in the courtyard; getting flowers from Liz’s garden. Marjie can no longer read or follow a TV show. Now, if Marjie is not enjoying a program or event she will get up and leave or try to leave; alternately, if she is enjoying herself she
will try to touch and look at the object of interest thereby engaging with things. She still says “yes” and “no” appropriately. According to Liz, learning what works is sometimes a trial and error process. Liz uses humour which always works in conjuring up old memories. Because Marjie is one of the younger residents she often disengages with her surroundings because she cannot identify much with the older age group as they are not her peers. For example, the music and movie selections made by staff for residents are for an earlier generation.

The PSW, Teresa is 46-55 years old. She has worked in the home full-time for 17 years. She has a bubbly personality and a loud expressive voice. When she entered the room, it was clear she was there. This may have been her trademark so that the residents would know it is her. Marjie picked up on Teresa’s enthusiasm and energy as soon as Teresa entered the room by standing up as if ready to go somewhere together. Teresa used to take Marjie for long walks when Marjie was physically stronger and could walk without the wheelchair. They still go for walks but less often than before. Teresa was optimistic about Marjie. In our interview she told me that Marjie still maintained many abilities and just needed the right kind of care with a lot of patience. She believed she brought this care to Marjie each day.

Theresa believes Marjie can still express pleasure. She told me that when Marjie sees her husband her eyes light up, she is happy and she strokes his hair. If Theresa calls out to her, she will look up and smile. Marjie’s face lights up when she sees familiar people. Marjie likes music and will snap her fingers and tap her feet and will occasionally dance. According to Theresa, she and Marjie have a very good relationship. Marjie can say simple words and knows her name and her husband’s name. Theresa stated, she
“didn’t lose it completely”. Marjie also enjoys pets. A therapy dog comes on Tuesdays for a visit. Marjie also likes sweets, but is currently on a reduced calorie diet, so Theresa limits this pleasurable treat. Marjie’s facial expression is often telling of how she is feeling. Theresa knows right away how she is doing based solely on her facial expression.

i. Video recording: Marjie and Liz

Liz chose to demonstrate how much Marjie likes chatting, social contact and ice-cream for the video taped segment. I met Liz and Marjie on the unit where Marjie was sitting with her private caregiver/companion. Marjie, Liz, her companion and I walked down to the main lobby where we sat in the café in a corner table. It was quite busy with many people sitting around the main atrium as a concert had just finished. I began taping when we sat down at the table. Liz talked with Marjie about what she (Liz) was occupied with, like cleaning up her house readying for a special occasion; about her garden and that there was now snow on the ground and even about her nail polish. She also asked Marjie if her husband had been in to visit her and talked to her about their mother’s health and other family updates. All of these topics also opened opportunities for Liz to reminisce with Marjie. For example, when Liz was telling Marjie about her garden, she asked Marjie if she remembered her own garden and stories about growing up and doing chores in the garden. Marjie listened, nodded, made eye-contact with Liz and was fully engaged in the conversation.

Later in the visit, Liz asked the companion to buy Marjie some juice, but the companion returned with ice-cream. Marjie’s eyes lit up and she smiled. She sat up straighter and had her hands ready to accept the spoon loaded with vanilla ice-cream. Marjie initiated sharing her ice-cream with Liz, by offering her a spoonful:
“That's nice, that's nice of you, you're gonna share with me, can I have a taste. MMM Oh delicious! Okay you can have some more now. It's really good ice-cream actually, now that I've given it a taste. She loves ice-cream. I forgot about ice-cream. You'll eat it all up. There you go. That's your favourite thing in the whole world is ice-cream”

Liz also had a taste of the ice-cream and Marjie did not object to sharing with her sister. Marjie’s happiness was visible through her facial expressions including smiles and laughs and her body language including nods and participation in the social aspect of this interaction. In that moment, Liz remembered just how much Marjie loved ice-cream even saying that it was her favourite thing in the world. Marjie smiled and nodded, seeming to be in agreement with Liz.

ii. Video review: Liz – declined.

iii. Video playback: Teresa

Teresa watched the beginning of the video with Marjie and Liz and commented that she understood what she needed to do for her video. She said that she and Marjie had their own special relationship and that she would show me this. I ended the video review before the recording was fully played out and mentioned to her that this visit included, being off the unit, eating ice-cream and making jokes and reminiscing with Liz. She agreed that she would do something similar.

iv. Video recording: Marjie and Teresa

After reviewing the video-tape of Marjie and Liz, Teresa and I met later in the week for her to demonstrate something similar for her video segment. Teresa did not take Marjie for a walk off the unit down to the café. Instead, she chose to show me how much Marjie enjoys dancing and how the two of them interact together. The video recording was done in Marjie’s room. Teresa turned on some familiar music (a song which Marjie
enjoys). Teresa began snapping her fingers and she and Marjie danced to the fast paced music in the middle of the room. Teresa took both of Marjie’s hands and swung them from side to side and they danced for about 3 minutes. Prior to the dancing, Teresa had brought some vanilla ice-cream for Marjie.

“You can have it Marjie. You like ice-cream eh? You like ice-cream? Yes, of course you like ice-cream. So what did you do today? Marjie, did you play with the "poom boo" (name of stuffed toy). What did you do today? Eh? Eh? What did you do today? Mmmm it's good eh?”

Marjie’s face lit up as she was offered the ice-cream and ate all of it with some help with filling up the spoon from Teresa. Teresa knew that Marjie liked ice-cream very much, but there was none readily available in the kitchen, so she had made a special effort to order a vanilla ice-cream just for Marjie. While sitting down in her chair, Teresa placed a teddy bear in Marjie’s lap. Marjie enjoys holding soft stuffed toys and her room had several of them on the chair and bed.

Teresa constantly talked to Marjie giving her positive feedback. Teresa fixed Marjie’s glasses when they appeared to slip down too far on her nose. Teresa also offered to wipe Marjie’s runny nose. Teresa was constantly taking care of Marjie. She asked her if she liked the music and if she liked dancing. Teresa did not engage in any reminiscing with Marjie as Liz had done, but did tell Marjie that they would go for a walk to see the flowers when the weather got warmer. Liz also talked about gardening with Marjie as Marjie enjoyed gardening all her life. Like Liz, Teresa also asked Marjie if her husband had come to visit (Teresa was coming in for the evening shift and may have missed his visit earlier in the day). Teresa planned to take Marjie for a walk downstairs to the main lobby where there would be some music later on in the evening and she told Marjie that
they would go downstairs for a walk later on. Marjie smiled and nodded when Teresa invited her to go off the unit.

v. Video review: Teresa

Teresa watched the video and commented on how happy Marjie is to get up and dance around. She told me that Marjie loves music and pointed out her toes tapping and the smile on Marjie’s face. Teresa said that Marjie loves ice-cream but does not get to eat it often because she had gained some weight after moving in and was now on a reduced calorie diet. Teresa also commented that Marjie is not holding her neck/head up as she used to. She was concerned that Marjie was ‘getting worse’. She said that Marjie is always ready to go for a walk with her, and planned to take her for a walk after we concluded our meeting to review the video.

Case Study 6: Sylvia, her daughter Ivy and her PSW, Abby

Sylvia is 93 years old and has lived in the nursing home for six years. She has moderately severe dementia which is stage 7a on the FAST (Reisberg, 1988). Sylvia is a widow with one daughter. She is a short woman with grey hair and many wrinkles on her face. She maintains the ability to walk with the support of a walker. She still has the ability to speak but has mild aphasia. She requires full assistance with her ADLs due to her agnosia.

On the day I met Sylvia, she was sitting in the main dining room area that was a hub of busyness since it was close to lunch time. She was sitting in a chair beside two other residents. She had a big smile on her face. This was characteristic for Sylvia according to her daughter and the PSWs who know her. In fact, she was described in her medical record as euphoric. Thus, she always laughed and smiled, even if it was not
appropriate to do so. I never visited her room since we always met in public areas, so I do not know what type of decor her daughter provided for her mother.

Her only child, a daughter, Ivy is in the 56-65 year range but looks closer to 65 with short grey hair and thick rimmed square glasses. She visits her mother four times a week for about half an hour each time. She usually comes at lunch time so she can help cue and encourage her mother to eat. Sylvia has not been eating enough and so Ivy sits with her at the dining room table to lend her support. In the interview with me, Ivy expressed her own fear of getting Alzheimer’s disease or some kind of dementia. She and her mother were never close and her mother was a strict and unkind parent much of the time, so she found it ironic that Sylvia is now euphoric and that she has to be her primary care giver. Her relationship with her mother is different now in that Ivy became an advocate in the nursing home for her mother. For example, Sylvia only likes toasted bread with her meals and this was not communicated to the food service staff consistently, so Sylvia would often remind them to do this regularly so that her mother would find the bread appetizing and perhaps eat more.

Sylvia had a transient ischemic attack at home and as a result spent about a year in hospital rehabilitation prior to moving to the nursing home. Before rehab and prior to moving into the home she used to attend a day program. She used to walk from her apartment to the day program and lived alone without any help. At home Sylvia’s routine was to leave home by 8am to arrive at the day program by 9-9:30am. She would have lunch there and return home, have an early dinner and early night. Sylvia knew many of the shop keepers along the street and would drop in to say hello on her walk to the day program. Ivy would check in with her daily. It was difficult for her family to accept that
Sylvia was becoming less independent and unable to live alone because she had always been strong and healthy, and managed living alone. Sylvia worked as a seamstress and enjoyed embroidery and smocking in the past. She never enjoyed cooking nor did she enjoy mealtime.

*Past Pleasures*

Ivy used to be able to talk, shop, and reminisce with mother. Today her mother can no longer have a conversation, no longer asks questions. Her previous personality was strong willed and influential on Ivy. Ivy felt that there was a reversal of roles, whereby she is now mothering her mother. Today Sylvia struggles to talk.

*Current Pleasures*

After moving into the home she adjusted well and is viewed as having a happy and social personality. She attends programs including sing alongs or bingo but requires a lot of encouragement to go. Ivy believes that her mother cannot follow along, but it is the change of venue that is most valuable to her. She continues to be a picky eater; however, she does enjoy coffee in the morning.

Ivy knows when her mother is uncomfortable by her facial expression, posture, sitting position. On a good day her mother will ask “What’s next” or “What’s happening”. According to Ivy taking her mother out has become too difficult with respect to getting in and out of a car so they no longer go out to the hairdressing salon, nor out to Ivy’s home for dinner. During her visits with her mother, they share hugs, kisses and touch, warmth and closeness are comforting and pleasurable to Sylvia.

The PSW, Abby, worked at the nursing home for 20 years and has worked with Sylvia since she moved into the home. In her interview with me, her expertise was
apparent. She was thoughtful about how her approach influences the resident’s response. She uses physical affection including hugs and hand holding to reassure Sylvia when she becomes anxious about a situation. She also stressed the importance being patient with Sylvia. She knew that Sylvia liked certain movies and could still appreciate watching them.

Abby believes Sylvia still experiences happiness, pleasure and joy. Abby sees that Sylvia responds to her in kind, i.e., if Abby is happy, Sylvia will also smile and look happy. Abby knows that Sylvia likes music, ball tossing, and companionship. Abby feels that if Sylvia sees a serious expression on another person’s face, Sylvia will become worried. Sylvia relies on reading facial expressions and knows the difference between happy and unhappy expressions in others. For example, how well morning care goes is dependent on how you enter the room and approach Sylvia. Abby gave the example of SARS (an outbreak of severe acute respiratory syndrome affecting care facilities and hospitals in the city) when all the staff wore masks. Sylvia became nervous when she could not recognize the faces of staff so Abby would lift her mask momentarily, say ‘it’s me’, smile and Sylvia would immediately recognize her and feel comfortable. Abby feels that Sylvia knows her and likes her, that she also has a good relationship with Ivy. Abby talks to Sylvia all the time, telling her what she is doing, what Sylvia should do, and she asks about Ivy. Abby has to use her judgment because Sylvia cannot respond to tell her if she is not feeling well, but Abby feels that she can tell by how Sylvia responds. She tells me that the key is not to force Sylvia or to rush her to do something or she will get agitated, especially at ‘feeding’ time. Abby has ‘little tricks’ that work, e.g., will give a student the assignment of helping her with eating, because they have more time.
According to Abby, Sylvia likes going for walks and likes for you to sit down and talk to her at her favourite seat which is in front of the window.

*i. Video recording: Sylvia and Ivy*

I video taped Ivy meeting Sylvia in the main living room area of the home. Sylvia was sitting in her favourite chair adjacent to the hub of activity, the “nursing station” and in front of a large window with bright sunshine beaming through. Ivy greeted Sylvia with a hug and kiss on the cheek. They held hands and Sylvia was smiling from ear to ear. Ivy sat in the vacant chair beside Sylvia and chatted with her about how she was feeling. Ivy then escorted her mother to the dining room telling her that lunch was going to be served soon. I continued taping and walked over to the dining room table where Sylvia sat with three other residents for meals.

Ivy praised her mother during the meal and asked whether everything was to her mother likes. “That's a girl, that's a girl. I thought you would enjoy the orange juice, no? You don't like that?” The orange juice was sour and Sylvia’s facial expression led Ivy to know that she did not like it. The resident seated at the table beside Sylvia’s had a birthday celebration and several family members were gathered around that table, including a lady holding a baby. Sylvia was looking over at the baby and clapping and smiling showing her happiness with seeing a baby. Sylvia did not eat very much of her lunch. This was typical. Her daughter felt the video demonstrated Sylvia’s sociability which is the source of most pleasure for her mother.

*ii. Video review: Ivy*

Ivy briefly watched the beginning three minutes of the video with her and her mother, Sylvia. She told me that she did not need to tell me when her mother was happy.
Her mother’s euphoric temperament, laughter and smiles were obvious and the most concrete indicator of Sylvia’s affective state. I agreed and we did not continue to review the video together.

**iii. Video playback: Abby**

I showed the video of Sylvia and Ivy to Abby. Abby, the PSW, watched the video with Sylvia and Ivy and told me that she would not sit at the lunch table with Sylvia as Ivy did because she would be busy feeding other residents, but that she would sit and chat with Sylvia instead.

**iv. Video recording: Abby and Sylvia**

Abby chose to demonstrate a social chat between herself and Sylvia without the meal. I filmed Abby greeting Sylvia as she sat in her favourite spot. Sylvia smiled and laughed as she saw Abby. Abby took her by the hand and sat next to her. There were several other residents seated in the adjacent sofa and one of them asked for a drink of water from Abby. Sylvia appeared nervous and held onto Abby’s hands indicating that she not go away. Abby explained she would be right back and did return momentarily to Sylvia’s side. Abby chatted with her about what she would do for that day and asked her how she was feeling. Sylvia answered with short answers but mainly smiled and held hands with Abby. Sylvia is euphoric and smiles most of the time, however, she did demonstrate dislike for the sour tasting orange juice with Ivy and also became upset with Abby’s leaving soon after sitting down to chat with her. Therefore, she does display an appropriate range of emotions although the positive emotional displays predominate.

**v. Video review: Abby – declined.**
Case Study 7: Sammy, his daughter Lindsay, and his PSW, Violet

Sammy is a 91 year old widower, who has lived in the nursing home for six years. Sammy is in the middle stage of dementia which is stage 7a on the FAST (Reisberg, 1988). He requires full assistance with his ADLs and no longer has the ability to walk, so he is in a wheelchair. He still has many verbal abilities with a large vocabulary although there was marked word finding difficulty and confabulation in our interactions. He was outgoing and social when I met him.

Sammy’s daughter Lindsay participated in the study. She is a woman in her late 50’s or early 60’s with shoulder length curly greyish hair. She dressed conservatively and wore a beret the day we met. Lindsay visits every few weeks since she lives out of town but talks to her father on the telephone whenever he is able to follow a conversation, which seems to depend on the way his day started out and how he is feeling. Lindsay has one sister who visits as well. Lindsay described her relationship with her father as somewhat of a ‘daddy’s little girl’. She told me that throughout her life, her father always made her feel better and when she was growing up he would often take her side in teenage disagreements between herself and her mother. Her fond childhood memories are sometimes a subject of reminiscence when she visits her father these days. She is married and her husband accompanied her to this visit, but remained outside of the room during our interview and subsequent visit. She was proud of her father’s past achievements as a prominent professional in the community.

When I met Sammy he was sitting in his wheelchair in his room watching a fishing program with his private caregiver sitting in the chair reading a magazine. His room is outfitted with the standard nursing home furnishings. The walls are busy, filled
with his art work from over the years. There is a television and a radio along with a window sill filled with pictures of family and grandchildren, a plant and some greeting cards. He greeted me as if he had known me all his life, with a big “Oh, hello!” He was smiling and gesturing for me to come into his room. Sammy had met me once before when I was briefly introduced to him by a colleague.

He moved into the nursing home along with his wife from a retirement home where they had previously lived together. Prior to moving into the nursing home, Sammy was increasingly forgetful and would leave the oven on, burning things and would get lost when he was out driving. These changes eventually culminated in their daughters’ decision that both he and their mother move to the nursing home. His wife passed away six years ago. Sammy was very much in love with his wife but found caring for her burdensome; after she died he seemed to have a new lease on life.

*Past Pleasures*

He took up painting, pottery and ceramic work. He continued to take interest in gardening, baseball and going out to dinner and a show. He has now lost the ability to read and no longer swims, plays golf, or fishes. Sammy is no longer able to carry on a telephone conversation with his daughter. He may also become agitated during outings and therefore going out for dinner or to the theatre is no longer feasible.

*Current Pleasures*

Sammy currently takes pleasure in chatting with others in the home, singing familiar songs, rhyming, spending time with his private companion, mealtime, listening to classical music, watching fishing programs on TV and looking through magazines.
He worked as a health care professional and retired at 80. Lindsay said her father has always been social and outgoing with a congenial, friendly and peaceful personality. He maintains a good sense of humour. According to Lindsay, Sammy had the ability to always make you feel so special no matter who you were. He likes to be told “I love you”. He likes mealtime, likes to eat, and likes cookies, ice-cream, salmon, coffee, water, coca-cola. In communicating he will sometimes revert into his mother tongue. He reminisces about his very young days. Conversations about fishing trigger smiles. He sleeps when he is bored. He enjoys making others smile.

His PSW, Violet, has worked with Sammy off and on since he has been living in the nursing home. The male PSW who usually looked after Sammy was on extended leave and so Violet had taken over his care. Violet was somewhere in the 46-55 year age range and had more than five years of experience working at the home. She attended graduate school in her home country. Violet was careful in our interview. She, more than any of the others, made a concerted effort to describe her professional approach to care. I believe boundaries were important to her because of Sammy’s tendency to be uninhibited towards female staff members. She believed that he still had many pleasurable things in his life and thought that giving him personal care was extremely challenging due to his physical aggression including hitting, yelling and kicking. She indicated that once his physical care was completed, he was a different person to deal with. Violet cared for Sammy and worked towards redirecting his overtly flirtatious actions and comments in order to maintain her professionalism.

Violet has worked with Sammy for approximately five years. She knows that Sammy still has the ability to express positive emotions. Violet is uncomfortable when
Sammy asks for hugs and kisses and in order to maintain her professional boundaries she will sing with him or dances with him or puts on the TV to distract him or change the conversation. Sometimes she gets the help of a co-worker. She said that he participates in all of the activities with help from PSWs including herself. He enjoys the social tea and community music programs. She also does some one-to-one activities with him. For example, she will sit and chat or do light exercise, telling him to raise his arms or point to his toes. Violet believes that Sammy likes the attention he gets in social situations. He makes jokes and smiles with everyone. He likes food (juice, coffee, bread, and muffin) and she gives him choices with food but not with other things like personal care as he would likely refuse showers. Violet relies on his facial expressions and body language to gauge how he is feeling and responds appropriately to him.

i. Video recording: Sammy and Lindsay

Lindsay decided to have her video tape done in Sammy’s room during a typical visit as Sammy’s most pleasurable interaction is socializing, singing, chatting about his favourite pastime, fishing and telling jokes. He also enjoys eating, but that was not included in this interaction. Lindsay greeted her father with a hug and told him it was nice to see him. He smiled and told her to sit down. The conversation centered on fishing. Sammy was watching a fishing show on TV earlier in the day and wanted to continue talking about fishing as if he and Lindsay were going to go fishing. The following is an example of Lindsay’s verbal interaction with her dad:

“You've taught me how to put worms on a hook, remember? Thread it on (gestures with fingers). Do you remember what you used to do, Dad? I'll tell you this, see if you remember. You used to take a syringe (says to Malini, "this is the truth"), you used to take a syringe and you would put air in the worm, you would puff the worm up with air, so that the worm would float around and like this in the
water, would float around and then the fish would go (makes an animated sound) and eat the worm. Do you remember you used to do that? …

Sammy: Yeah.

Lindsay: And he also used to put cornbread. Corn bread, he used to put my grandmother's cornbread on the end of the hook and the worms and the fish loved it right? Bass?

Sammy: Are you ready? You're not going to go... (points to Lindsay’s clothing)

Lindsay: Fishing like this (gestures to her blouse) with a blouse?

Sammy: No.

Lindsay: What should I wear?

Sammy: Do you have a pair of pants.”

Sammy believed that Lindsay would take him fishing, the conversation shifted from going fishing to reminiscing about the things that he taught Lindsay to do when they had gone fishing. Lindsay also took some of the framed family photos from the window ledge and showed them to Sammy telling him about his grandchildren pictured in them. He smiled and made eye-contact with her throughout their conversation. Sammy also liked being on camera. He gestured to me a few times, looking into the camera and asking me to come along on the fishing trip.

His private companion was also in the room for a part of the video taping and he invited her to get ready to go out dancing. He told her to get his shoes ready. Lindsay told me that Sammy and her mother used to go out dancing earlier in their marriage. Sammy reminisced about his past pleasurable activities with the three of us during this visit.

ii. Video review: Lindsay – declined.

iii. Video playback: Violet

I showed the video tape of Sammy and Lindsay to Violet, his PSW. Violet watched five minutes of the 38 minute video recording with Sammy and Lindsay. She told me that she was too busy to watch the entire video, but that she would be able to show me how she and Sammy socialize and activity that he takes pleasure in. I agreed
and pointed out to her that the remainder of the video contained conversations about fishing and reminiscing about going out dancing as well as looking at family pictures that were on the window ledge in his room.

iv. Video recording: Violet and Sammy

Violet told me about her struggles to constantly maintain and reinforce professional boundaries with Sammy. He had a tendency to be uninhibited and asked for kisses from PSWs and other female caregivers. He was also agitated during morning care and sometimes became physically abusive towards her and other staff members. Despite these challenging caregiving situations, Violet told me that Sammy was a nice man and that he did still enjoy life and have pleasurable moments. During the video interaction, Violet chose to demonstrate how Sammy takes pleasure in singing and how he also enjoys being praised. Violet met Sammy in his room. I re-introduced myself to him and told him I would be taping him and Violet visiting in his room. Violet started off the visit with saying hello to Sammy and telling him she was his friend. She also asked him if he wanted to go downstairs for coffee and a muffin. Violet told Sammy he was having his picture taken by me and to smile for the camera. Sammy looked over at the camera and made a funny face. His mood was playful and jovial.

Sammy reached out and held Violet’s hand and pulled her closer to him. Violet politely redirected Sammy’s attention and asked him if he was in the mood for a song. He smiled and did not disagree so she began singing a familiar song to him. He joined in with waving his hands as if conducting the music and humming along with some words interspersed. After they finished singing, Sammy blurted out “Bravo!” Violet pointed out some of Sammy’s art work that was hung on the walls in his room. She told him that he
was a very good painter and asked him if he painted the pictures. Sammy paid full
attention to Violet, and seemed to appreciate her praise of his paintings. He did not say
anything, but he had a proud expression on his face. She also told him about his previous
profession and reminisced with him about what a wonderful job he did for the public.
Again, he appeared to be proud to hear such compliments.

Violet’s visit with Sammy was similar to Lindsay’s since they both chose to share
stories with him and to chat with him in his room. Lindsay did not sing with Sammy, but
did tell me in the interview that Sammy enjoys listening to music.

v. Video review: Violet – declined.

Summary of Video Data Results

The Role of PSWs in the creation of pleasure

Two themes emerged from analysis of the video recorded data. First, pleasurable
interactions are replicable and second, PSWs are knowledgeable about how to create
moments for pleasure in residents with dementia. With regard to replicability, PSWs did
not consistently replicate pleasurable activities demonstrated by family members in
residents with moderately severe dementia which is stage 6 to 7b of the FAST (Reisberg,
1988). PSWs did different things in Case 1 and Case 7, and part of this was owing to the
appropriateness of PSWs replicating family member interactions. PSWs consistently
replicated pleasurable things demonstrated by family members in residents with very
severe dementia which is stage 7d and 7e of the FAST (Reisberg, 1988).

The video recording analysis showed that PSWs are knowledgeable about what is
pleasurable in residents. A review of the literature prior to conducting the research project
did not provide rationale for regarding PSWs as knowledgeable informants about the
residents but rather as health care workers who required education about resident preferences and personhood centered care.
CHAPTER 6: RESULTS

The notion of pleasure in moderately severe to severe AD

Introduction

In this chapter I present case study data that illuminates the concept of pleasure in a long-term care facility, particularly how the family members describe pleasure and how they go about eliciting pleasure in the resident and, similarly, how the PSWs describe pleasure and how they go about eliciting pleasure in the resident.

It became evident that residents with moderately severe Alzheimer’s disease maintained some ability to initiate enjoyable things whereas those with more severe impairment were no longer able to do this and, therefore, relied on initiation from others. In advanced dementia when there are no longer observable signs present, caregivers (family members and PSWs) described meaningful responses from the person which they interpreted to be indicative of a positive interaction. The caregivers provided rich descriptions of how they were able to connect with the residents with advanced dementia, yet this is a one-sided view as the response from the resident is no longer present. The categories that emerged from the thematic analysis (Braun & Clark, 2006) of each case study are used to organize the data. These are: sources of pleasure (lost, retained and new); family members and PSWs knowing what to do to elicit pleasure; indicators of pleasure; and continuity of personality.

Sources of Pleasure: lost, retained and new

A cross-case analysis showed that all family members who were interviewed identified sources of pleasure that were present before dementia and that are now lost, as well as ones that were present before and are retained, along with new sources of pleasure.
In contrast, but understandable, only one PSW referred to a lost source of pleasure. The other PSWs focused on current sources of pleasure as they did not have the historic perspective that family members had. PSWs who worked with residents over time however, could describe declining abilities that resulted in lost sources of pleasure, but not the lost sources from life before institutionalization. As with any individual, and certainly for these residents, the sources of pleasure are unique; they are not universal.

Lost pleasures

Unique sources of pleasure were lost in all residents. Residents lost sources of pleasure that require self-initiation. For example, if the resident could no longer walk then he or she cannot take pleasure in initiating walking. Other pleasures are lost due to declining abilities related to dementia. For example, if the resident cannot read, then he or she cannot take pleasure in picking up a book to read. Often these residents have lost the intellectual capacity to do pleasurable things. Even when family members initiate the activity for the resident, the pleasurable activity is abandoned, perhaps owing to changing tastes. Family members listed lost pleasures: watching TV, reading, spending time with friends, cooking, baking, sewing, crocheting, watching movies, playing cards, and teaching. Several case study exemplars are given to illustrate how family members described lost pleasures in the residents.

Emma and Susie

Susie described Emma’s cognitive losses:

“And now I find it hard to get her to watch the TV, she wants it “off” “put it off”. Sometimes I can put it on; I don’t think she gets what’s happening, you know, I don’t think she understands, the same way if she was reading a book. She can read very well, I walk along and she’ll read a word, you know, that’s on the door, on the wall, I mean she can read but she can’t comprehend. The comprehension is not there so it’s
very hard to tell her a story or tell her what happened or you know it’s like, I find it very difficult.” (GFi292)

“You can play a game of rummy with her; she’s been pretty good with the cards up until now. But now she just doesn’t play anymore, now, or seem to want to play anymore. But I mean last year, she was still playing cards and doing well, I mean, beating us. I think the minute it’s numbers, something that she’s very familiar with that she can do, she can still remember.” (GFi330)

The lost intellectual ability to comprehend robs Emma of a previous source of pleasure.

As Susie told me, when friends stop calling or visiting, it is family who usually remain:

“You know, up until about a year and a half ago her friends were calling her and speaking to her on the phone and now they don’t anymore because they get no, it’s not response… See she’s got no friends here, because from when she arrived here she didn’t have the ability to make a friend so all the, it’s family, you know its family which there are a lot of us.” (GFi397)

Mary and Patsy

Patsy described the types of things her mother, Mary, kept busy with when she lived at home:

“At home, she within reason of her capabilities you know physically or her health she was as active as, you know, she would be at home, basically a lot of cooking, lot of baking… a lot of television, avid, avid reader, oh MANY novels, loved to read, read, read, so she would get up, couldn’t sleep in the middle of the night, would get up and read… creative on that side, I would say, big on, she was a very, very good knitter, she could crochet.” (FFi7)

Mary and her husband led an active social life, but can no longer do the things that they once enjoyed together, below are some of the lost pleasures Mary no longer partakes in:

“Well they’d go in their groups. They would go to theatre and she liked to go to the movies, moviegoer. And also, for, I would say for maybe 18 years they would travel during the winters and she would be, am we signed her up for, well they would both go for chair aerobics, which she used to go to once or twice a week, which was an added thing there.” (FFi37)

Anne and Emily

Emily told me that her mother, Anne has lost many of her hobbies and pastimes:
“…she was very athletic. She would also golf, and during the season she would play like 18 holes a day and then she would swim lengths for at least a half hour. So she was an extremely physically active person and really enjoyed that part of her life and I think one of the things about her illness that I’ve always worried about for her is this lack of physical activity and what it must feel like for her to be in sitting all the time or laying and not being mobile. And I’m just grateful for that one day a week where they come and take her for a walk because I think that for her that’s probably a very pleasant experience for her to move her body.” (EFi145)

“She was a good cook but she really liked to go out to eat, and you know she loved to go out for a nice Chinese meal or lobster or this or that or you know and she always had very bad eating habits. She was always very thin. She really didn’t eat breakfast, didn’t eat lunch, and then she ate this huge dinner and she worked out pretty much every day… So she would always have a dessert, but she loved going out to eat. That was always her favourite cause if it was the family we were together everybody was always in a little more festive mood.” (EFi352)

Friends who no longer call or visit were a source of lost pleasure for residents. Emily talks about Anne’s outgoing nature and adoration for her friends which was a past source of enjoyment for her mother:

“She’s very outgoing personality, she’s got a great sense of humour, she’s hysterically funny, she adored her girlfriends and she made wonderful friends that she had for many years.” (EFi194)

Marjie and Liz

Marjie’s sister, Liz talked about Marjie’s past pleasurable activities:

“So she was kind of a housewife, she didn’t have hobbies as such… I was always the knitter, she would get tangled up in the yarn, she liked gardening, she was big on gardening and she had a dog who was a crazy Irish terrier who needed lots of walking and so she really I think she and that dog if you measured them for mileage in those days, she would be out for, oh three, maybe three hours a day, they did a lot of walking.” (CFi61)

“well she was an avid reader and she hasn’t been able to read in at least a year and a half to two years, I would say, I don’t think it, that the letters mean anything to her anymore, yeah, but she was quite an avid reader and we could discuss books and things like that.” (CFi118)

“I did try photographs with her, that didn’t work very well, she, visual cues are really bad, that’s one thing that I noticed with her, visual clues are amongst that was the first thing that she lost, when she was living at home, I must have walked
around the block with her thirty-two times, around the block, never crossing the road just on the same sidewalk, we’d get to her house she never knew what her house was, coming at it from either direction, you know, like visually she did not know…”(CFi227)

Family members often try the things that were once pleasurable and when repeated attempts to elicit a response fail they then realize that this source of pleasure has been irretrievably lost. There is a distinction between the resident merely having a bad day and not responding to them as usual, versus deciding that that source of pleasure did not work on several different occasions, therefore concluding that it is irretrievably lost.

*Marjie and PSW, Theresa*

PSW, Theresa noticed that Marjie had lost some abilities since her admission to the nursing home and therefore lost some sources of pleasure:

“…she use to like walking, but I don’t know, something inside her like changed, it was like even her head, like she’s not holding her head up.”(CPi56)

*Sylvia and Ivy*

Ivy spoke proudly of her mother, Sylvia’s creativity, a source of great satisfaction and joy in the past, but no longer:

“She was a marvellous seamstress and earlier in her life she did mainly decorative things, embroidery and smocking. She was extraordinary….That was truly her craft.” (BFi154)

*Sammy and Lindsay*

Lindsay told me that Sammy could no longer watch TV nor could he read, although he once enjoyed reading very much:

“A lot of people will put on television and I’m really not sure how much he can focus, like he really can’t read anymore.”(AFi225)

Sammy took great pleasure in fishing, but no longer fished:

“He wasn’t really much of an athletic, he mostly adored fishing.”(AFi264)
Lindsay made an effort to take her father out of the nursing home to places and events that he always enjoyed:

“I took him out, we went to Stratford a couple of times, we went to baseball games, because they always loved baseball, from the time he was young he loved baseball, and, so we went out, they loved going out to dinner, so I even took him out to dinner last year, we rented a wheelchair taxi and we went out for lunch.” (AFi60)

None of these pastimes are possible now since Sammy becomes agitated when he is in unfamiliar surroundings.

 Isa and George

George finds it difficult to know whether or not Isa can still understand him. They used to share many enjoyable conversations in the past. He describes how he tries to elicit pleasure from Isa by updating her on the family but that that ability to understand his conversation may be lost:

“I talk about the children, and the family and tell her that so and so came to see her, is going to see her, but, I don’t know how far, how much she knows, what is it’s impossible, almost impossible for her to know.” (DFi230)

The family members all talked about past pleasurable things that their relatives no longer did. Many of these pleasures were lost due to the declining abilities of the resident. Some of these abilities were lost to dementia while others were lost to co-morbid illnesses. Sources of pleasure were irretrievably lost because the resident’s diminished ability to initiate and follow through with the activity even when initiated by a family member.

Retained Pleasures

Residents lost the ability to initiate pleasurable things and therefore relied on caregivers to provide opportunities for enjoyment. Retained pleasures are the things that residents still enjoyed but could not initiate for themselves. Family members and PSWs
both felt that the residents maintained sources of pleasure from their past, pre-illness. Family members could compare their relative’s current likes and tell me that these were maintained sources of pleasure. However, PSWs did not always know whether the sources were maintained from the past because they did not know the residents throughout their lives, but PSWs knew that the residents could still enjoy certain things from their admission date to the present time. The things that the PSWs described as pleasurable were similar, though not as extensive as those described by family members. Retained pleasures usually had to be initiated by another person, either a family member or PSW. The sources of pleasure that were maintained were passive activities such as listening to music, or tasting sweets. By passive, I mean that the person did not initiate these activities/interactions; instead, the familial caregiver or PSW was actively initiating the source of pleasure. Family members sought things that they could bring to their relatives and initiate for them. Other examples of retained pleasures: being praised; eating mainly sweet tasting food; listening to long enjoyed music; being dressed up; being with family; being with friends; and sitting in the sun.

*Emma and Susie*

Susie gave many examples of the things that Emma still enjoyed that Susie would initiate or suggest for the PSW to start with her mother:

“And the other thing that will make her happy anytime is to tell her how beautiful she looks.” (GFi168) “Take a picture of her and you’d make her happy.” (GFi317)

“You know my mother likes to help, she’s a big helper, she likes clearing off the table … She’s a helper and she likes to do things, and I say, you know, it would be so nice if the staff involve her a bit. If they got her to fold stuff, whether she can still do that I don’t know, but a year ago she could have. So maybe they could, I think it could be nice for the people on the floor to be helpers.” (GFi360)
Susie’s mother maintains her ability to socialize and enjoys attending group activities, and with encouragement from the group facilitator (usually a recreational therapist) will participate in dancing:

“...and eventually she started going to everything and loving it, being really happy. And now she’s like, gets herself to be the centre of attention. If they’re singing she wants to get up and dance in front of everybody.” (GFi149)

The recreation therapist who leads the dance group initiates the dancing for Emma by walking over to her seated in the circle of residents, some of who are already up on the dance floor in the middle of the circle with volunteers. Once Emma is pulled up to the dance floor, she continues to dance together with the recreationist. When the recreationist moves onto another resident, Emma sits down again.

*Emma and PSW, Jane*

Jane explained to me that she believed that Emma still had many sources of pleasure in her life in the nursing home. She felt that Emma still enjoyed visits from her daughters, attending social functions at the home such as afternoon tea and having Jane polish her nails and apply make-up.

“They do enjoy life by touching, feeling, they like to be touched, they like to be hugged and many times when you may think that they do not understand. They do understand tenderness and loving touch. You find that they really, really appreciate it and I think even if you’re making them up or doing their face or doing their hair I think they realize what you’re doing and I think they still get pleasure from that sort of thing.” (GPi3).

The PSW clearly had given thought to and worked out ways of bringing pleasure to Emma and other residents. Jane gave examples of Emma’s retained pleasures:

“Over the years there has been some changes in her but right now, she shows that she’s always smiling or dancing or doing something like that.”(GPi42)

“She loves to do her makeup and she likes to stand in front of the mirror and say ‘you know she looks beautiful’ and things like that.”(GPi51)
Mary and Patsy

Mary had the highest cognitive abilities of all of the residents in the case studies. She has maintained the ability to watch TV as Patsy describes in our interview:

“Passive activities, that’s a given, you know watching TV, the music appreciation, she does play bingo here. Given the activities that are geared towards a person with this… illness, she participates in as much as her mood… it’s mood driven.” (FFi43)

Mary still takes pleasure in socializing with her friends at the nursing home during her daily visits with her husband:

“And keeping her out of that nurses station there, and out of her room, and downstairs where there are people and it’s a different scenery and I can attest to that because when, at night we socialize quite a bit, my dad when we bring her, my dad takes her down there every night, whether it’s for bingo, a concert, afterwards they have their group of friends and she socializes and then when it’s 8:30, it’s ‘do we have to go up?’” (FFi61)

Mary and PSW, Nancy

Mary retained the ability to socialize and enjoyed sitting in public places watching people go and come,

“We’ll often go downstairs and we’ll sit down there in the foyer to watch everybody coming and going. Or we’ll go outside and watch the buses go up and down the street or the traffic, so we’ll just go people watch.” (CFi152)

Anne and Emily

Anne is confined to a wheelchair and cannot walk on her own. She requires the full assistance of a therapist to be walked, yet Emily believes this is part of her mother’s maintained pleasures because she once loved walking so much.

“Because we feel even that little bit of walking gives her a sense of herself and it’s also good for her to move physically, you know for her to move a little bit. But it also, for her, when she’s been such a physical person, I just feel…I think she misses it.” (EFi161)
Emily and her mother share a special mother-daughter bond that Emily believes is a source of pleasure for her mother. She also describes her mother’s personality:

“So we were pretty bonded because I was her best friend for awhile. You know she didn’t have any friends when she first came here. Although she did make friends.”(EFi192)

“Well you know it’s really very basic, but I think a good day for her frequently involves ice-cream…. if you give her ice-cream she’s happier and I know that.” (EFi478)

Marjie and Liz

Liz believes that Marjie retains these pleasures:

“I think music, and I think animals would, I mean, she always was just, I always feel strongly that if she would have an animal to stroke from time to time that it would be very good for her… she loves music, any kind of music going… she doesn’t identify as much as the older residents would, but it’s still music and she still enjoys it.”(CFi128)

“She just loves being outside.”(CFi148)

“out for a cookie, an apple or some grapes and then come back and that gives her something to do and watch… when the gardens are out in the summer down in the courtyard, then we go around and look at all the plants because she is use to it, she had a great big garden and she loved her garden.”(CFi166)

Marjie was placed on a reduced calorie diet because she had gained weight upon moving into the nursing home. Liz describes how she brings her treats in moderation and also how flowers from her garden serve to brighten Marjie’s mood and to bring back pleasant memories:

“Last week or two weeks ago I had some cinnamon candies with me, cinnamon hearts, and I gave her one of those to eat, so she didn’t lift it from her hand to her mouth, so I finally put it in her mouth and I could see her kind of thinking, and I said ‘Is it chocolate?’ and she didn’t say anything and I said ‘it’s not chocolate is it?’ and she said ‘no’ and I said ‘is it good?’ ‘Uh huh’ and then I said ‘do you want another one?’ ‘Yeah’, so I thought something new that’s a little taste that she’s not going to get here, but she might remember from the past. So I won’t give her a lot of those, but every couple, so something that she would have had in the past that maybe, will trigger something. And in the summer when I come, the odd flower from my garden or something that she would have grown in hers, you know.” (CFi258)
This is a noteworthy example of the searching that family members do to keep bringing pleasure to the interactions with their relatives.

Marjie retained some ability to reminisce and appreciate humour and Liz describes how that takes place during a visit:

“I do use the humour with her because that always works and I do try and remember things from really early and tell her, I’ll say ‘remember this, remember that’, cause she’ll smile even if it’s just a name out of that whole phrase that rings a bell with her, there’ll be a reaction….I thought showing her pictures the same, or television or visual things isn’t registering with her, so I have to talk about things that she remembers instead or things that she did or that kind of thing, so that’ll trigger a reaction, so humour works, like today I came and I said ‘are you still making noise in the back corner’ and she started to laugh, so…” (CFi221)

*Marjie and PSW, Theresa*

Theresa, her PSW, often plays music for Marjie’s enjoyment:

“…music, like if you take her to the room and then you put on the music, you know she has the favourite music, you turn it on, and she listens and she just (demonstrates snapping her fingers) and you know… snapping her fingers and you know she, she IS with it, she’ll tap her feet and you know snap her fingers.” (CPi34)

Like many residents, Marjie still likes sweets:

“For example, after she eats dinner, she likes sweets, like sometimes if we go to the programs, if I have sweets, she’ll just grab it.” (CPi150)

*Sylvia and Ivy*

A retained pleasure of many years, coffee, is described by Ivy about her mother Sylvia:

“she LOVES coffee, and she used to, when I was a little girl she use to perk coffee in the morning and that’s what I woke up to the smell of perking coffee, which is probably a bygone (laughs) thing anyway, but she was very fond of coffee.” (BFi399)
**Sylvia and PSW, Abby**

Sylvia’s PSW, Abby noted that she remains social and likes to chat and sit in the social hub of the nursing home unit:

“She likes you to sit down and talk to her, even though you know… her favourite seat is that one in front of the window.”(BPi91)

**Sammy and Lindsay**

As Lindsay describes below, even though something may still bring pleasure to her father, it is not consistent. For example, Sammy usually loves the outdoors, but sometimes he also dislikes it:

“and so, so he used to, he used to and still, if we wheel him, but it’s either too hot, see it’s very difficult now because he’ll either say, it’s too hot, or too breezy, or too cold, and you bring him blankets, and, you know, so he used to Love to go and sit out there, and sometimes he still does.” (AFi121)

Sammy retains his love for singing and dancing and his sense of humour:

“Well we sing, and I tell him stories, and I joke around and he likes to make funny faces, now and like I wink at him, he used to be able to wiggle his ears. I’m sure he can’t do that anymore, but and you know funny things with your hands and he loves it if I dance around and pretend to dance and that… I put on nice music, he took us to the symphony and such when we were young, so I know he likes classical music so I put on Classical [radio station].”(AFi216)

Sammy maintains his love for food:

“He’s happy eating….He loves food…well he used to, like he used to love ice-cream and love salmon, but now it’s just kind of, it’s all kind of good; although he’ll say, I won’t say the word, but he’ll let you know if it’s not good!...But he has a very hearty appetite and he loves his coffee… and he loves Coke too, he always loved coke, coca-cola.”(AFi417)

**Sammy and PSW, Violet**

PSW Violet describes some of the things she does with Sammy in between care that demonstrate his retained social self:

“We, sometimes I sit and chat with him, sometimes I sing for him, I face him with me, sometimes I try to do exercise with him, I lift his hands and I say, ‘do this, do
that’ and he’ll do, sometimes he’ll respond to you…he likes that, he’s a sociable man.”(AP49)

Residents retained pleasures in the nursing home provided that a knowledgeable caregiver took the initiative to create an opportunity for that interaction or activity to take place. There is passivity about the maintained pleasures. Family members and PSWs provide opportunities to enjoy food, especially sweets and they also assist residents to attend music programs or turn on the radio or play recognizable music for the resident’s enjoyment. They also sing with the residents and use touch where appropriate for reassurance or comfort and pleasure. Retained pleasures centred on sensory experiences including taste, touch, sight and sound. Families and PSWs searched for new sources of pleasure as well.

New Pleasures

Family members described some new sources of pleasure in the residents. Given their knowledge of their relatives’ past likes, they were able to notice when something that was never particularly enjoyable earlier in their lives became a source of pleasure. New sources of pleasure are defined as the things that the resident currently takes pleasure in that they rarely showed an interest in, in years past. Family members were able to reflect on their family history to think of whether certain pleasurable things were new or continued from the past. PSWs were not able to describe pleasurable things as new since they did not have the past experience to draw on. Examples of new pleasures: sweets (used to be weight conscious); attending religious services; socializing (liked being alone); creative interests (pottery, painting with watercolours – usually driven by the organized activity programs in the home).
Emma and Susie

Susie explains that Emma now enjoys sweets as she no longer watches her weight:

“I mean food isn’t the most important thing in her life, but she’s always been very controlled about what she eats, so now she enjoys some things that she never used to, like ice-cream. She never used to eat anything that she thought would be fattening. Now ice-cream is okay.” (GFi275)

Mary and Patsy

Patsy talked about how Mary enjoys socializing off the unit:

“Another thing she gets pleasure from is, I believe she likes to listen to the conversations and hear what’s going on. And she may not have to be a participant, but to listen to it, it’s something to stimulate her and then when she has someone there who really is like on target, they’ll say “and Mary, what do you think, what’s your opinion?” and then she’ll say something!” (FFi191)

Mary takes great pleasure in hearing the voices of her loved ones, so her daughters and her husband make sure they speak with her regularly:

“I think her biggest pleasure which she will say is that she, when you call her on the phone, ‘hi mom, how are you doing?’, ‘Oh, much better now that, now that I’m speaking to you’, that’s her famous line and she’ll say it to my sister, she’ll say it to me, ‘and even better that my husband is here’, this line gets repeated all the time, so family members visiting excite her. And you tell her today her grandson is coming tonight and she’ll get really excited.” (FFi236)

“She likes attention, fussing over her.” (FFi261)

Mary was never a very religious person by Patsy’s account, yet since the home provides religious services, Mary now attends and enjoys the services:

“She does enjoy going to the religious services. She knows all of the songs….religious service participation, it’s short and she can follow, she can still read the book and that. That reminds her of her religion. She’s not a religious person. But she is in a facility that is more religious than what she came from, right, so...” (FFi395)

Sylvia and Ivy
Ivy and Sylvia share a new bond through outward signs of affection which is a new source of pleasure in this mother-daughter relationship:

“We just hug a lot and kiss a lot, we like to hug and kiss.” (BFi406)

“Well, I can tell you what I normally do if I have the time, in the afternoon, she’s often put to bed for a rest, so I often get into bed with her, like the bed is not flat out, it’s up and we sit in bed together and we watch TV together, but it’s not just the watching of the TV, but I think it’s the human, the warmth of another body, and so we hold hands and we’ll just snuggle.” (BFi420)

**Sammy and Lindsay**

Sammy developed several new hobbies when he first moved into the home which he took pleasure in doing. Lindsay describes the various crafts that he began to work with after her mother passed away:

“…he started doing painting, pottery, he did ceramic work, he did gardening, well he always loved gardening, but he did more gardening, he went to classes, oh, he made these lovely hand painted silk scarves, he loved doing ALL the crafts.” (AFi58)

Both the retained and new sources of pleasure required another person to initiate the interaction or activity and are transient in nature. The onus is on caregivers to be the source of initiation for retained and new pleasures in residents with dementia. This means that PSWs and family members struggle to know what to do and to figure out what to do with the resident daily or from one moment to the next.

*Family members and PSWs knowing what to do to elicit pleasure*

*Family members*

Families and PSWs talked about how they figured out what to do with the resident on a daily basis. Some families regarded themselves as intuitive ‘knowers’ while others used the “trial-and-error” approach based on knowing the resident’s past preferences and still others used a bit of both. Families and PSWs described knowing as a “learned putting
together of signals” (e.g., how one daughter’s approach towards her mother motivates her mother’s actions). Family members drew upon biographical meanings in generating ideas for creating pleasurable moments with their relatives. PSWs used trial-and-error and relied on family members for suggestions. Families in addition to drawing on past meaningful experiences (e.g., favourite food) developed a familiarity from being present in the nursing home and visiting regularly with their relatives. The extent to which a pleasurable interaction is possible depends on the overall health of the person with dementia (e.g., not having a urinary tract infection and being in discomfort). In some cases, the absence of discomfort was an indicator of whether or not the resident would be able to experience pleasure. Families made a broad assessment at the beginning of the visit about whether there were opportunities for pleasure present during that particular visit (e.g. sleeping alongside mother rather than keeping mother awake for conversation). This first example is about one family member’s assessment.

*Sylvia and Ivy*

There are mitigating factors to knowing whether the resident will be in the mood to experience a pleasurable interaction during a visit with family members. When Sylvia had discomfort due to an infection, her daughter, Ivy would not expect to go to an activity with her or do anything pleasurable during that visit. When I asked Ivy about how she can tell whether or not her mother is enjoying something, Ivy gave me an example about how she does her assessment and how she is able to spot urinary tract infections which are a common source of discomfort in her mother:

“Well, yeah, I would say this, she’s …I think I can tell, I don’t know if general staff can tell. And I don’t like I will say to her “mummy are you uncomfortable?, does something hurt you?” and I don’t know that she would be able to point to anything, but I feel, I can see it in her face. If she has a bowel movement I know
it… it is how she holds her body, yes I do believe that, and I do believe there is an appearance of distress, which is unusual, and so therefore it should be noted almost immediately and if she has a what do you call it? A U, T… [Malini: a urinary tract infection? A, U.T.I?]
yeah, it’s obvious that’s she functioning at an even lower level, I don’t know why they {referring to staff} don’t see it, so I alert them… facial, you know, it is facial, I would say that and certainly how she holds her body, but I don’t think she’s capable of pointing to her distress, no.”(BFi284)

Anne and Emily

Emily, Anne’s daughter, compares her visit with that of her sister who is unable to just sit and fall asleep alongside their mother during a visit even though she knows this is comforting to their mother. Her sister would rather leave and return when she can interact, talk and chat to her mother.

“And whereas I will come in and sort of be with her physically a lot and say “are you the best girl?” “Is this the best girl in the whole world?” I’ll talk to her like that… I was here one day and my mother was sleeping and I was sleeping and that was my visit with her, she was sleeping and I was sleeping in the chair beside her. But my sister walked in and when she saw we were both sleeping she left. So she would never just sit in a chair and just sleep with my mother you see….it’s a different visit… I think she comes in and has a short visit, like half hour is the max she’ll be here. I know sometimes it can take hours to try and make a connection, any kind of connection. And my sister and I don’t know if she still does, but she would come in and talk to my mother the way she always had.”(EFi441)

Emily knew that her mother could no longer appreciate a visit where news about the family and gossip were shared, which is what her sister would engage in with Anne. Instead, Emily learned that Anne derived pleasure from a quiet visit where the two of them would sit together and sometimes not say a word to each other.

Emily described her idea of how staff ought to care for her mother using the example of touch:

“And I guess in terms of quality of life and making her happy, I think with the shortage of staff and what my expectations are, I guess the only time I could see them actually connecting with her and making a special effort is during when they’re
feeding her, because they are with her for an hour and they could perhaps hold her hand, or touch her arm like this, you know. I certainly wouldn’t want them coming up and kissing her or hugging her because I don’t think she would like that, people who aren’t her family or her close friends to do that. But I certainly think holding her hand and maybe rubbing it or rubbing her arm would be completely appropriate and they have to be with her anyway, so instead of if the staff are in the dining room talking to each other… Instead of doing that if you have to be with a person for an hour to feed them and for the people who are very ill, I think that is pretty much the case, and you don’t have any other time to do quality of life, why not take that time to try and connect with the person as if they understand you and ask them ‘how they’re feeling?’ and ‘do they enjoy the food?’” (EFi325)

*Mary and Patsy*

Mary was much higher functioning than any of the other residents in the case studies therefore her daughter Patsy was often told by her mother that she was unhappy because she is living in a nursing home while her husband and children live separately. Mary is losing capacity but she can still indicate how she feels about her living environment, whereas residents such as Anne or Isa can no longer indicate such feelings. In people with more advanced stages of dementia, family members are forced to search for indicators of pleasure.

> Patsy knows that her attitude during the visit will affect how her mother reacts:

> “So as soon as you initiate that there will be something else happening then, the excitement kicks in.”(FFi78)

*Anne and Emily*

In the more severe cases of dementia, family members’ accounts about pleasurable and unpleasant things may be helpful. Emily shared her understanding of her mother:

> “If you give her chocolate ice-cream, which is her favourite food group, she might open her eyes, and I think that, and smile and engage you, and I think that is because she realizes that something nice is happening to her at that moment in time…Well she might make eye contact…or she might start talking…There’s talking, but mostly you don’t understand what she’s saying because it just sounds
When describing her mother’s taste for ice-cream, Emily shares her thoughts on what her mother is experiencing:

“And she still responds really well to it, like you know she always seems to be, she’ll just open her mouth and you know sometimes it isn’t really more than that, but you know that she knows in her heart that it’s something special for her.” (EFi491)

Emily considers herself expert in her mother’s care and expressed her belief that her mother is still able to hear and understand others:

“I think she understands a lot more than people realize…. well she can’t communicate, well if the person you’re talking about says “bache bra brrr” and their eyes are closed all the time and they can’t go to the toilet by themselves, and they can’t walk by themselves and they can’t feed themselves, you might think they’re not there.” (EFi289)

**Isa and George**

George, himself living with mild cognitive impairment, struggled to find the words, but was able to tell me about how he knows whether his wife, Isa is enjoying herself:

“Well, the only way that I know, I can find out is when I’m sitting next to her and she holds my hand, I, she holds my hand and she holds it hard… I’m sure that means that she wants, that she knows it’s me, because she doesn’t do that to other people.” (DFi119)

**Marjie and Liz**

In addition to trying out previously enjoyable candy such as cinnamon hearts as described under the theme of retained pleasure, Liz also used trial and error to help select the menu items for her sister Marjie:

 “…so I started to put a mix of things down, I know she always hated hot dogs and spiced meat and corn beef and there was one day every two weeks, or every week
on the menu, that that’s all that was on the menu and that was all they’d offer
and oh I’d say get her a fruit plate then, I don’t care because I know she’s always
hated it and it never agreed with her and I didn’t want her to have to eat hot dogs,
so there are things like that, and now when [her private caregiver] gets her a fruit
plate, like we know she’ll always eat a fruit plate, she loves fruits… So she gets
really enthusiastic, if there are, you know peaches or fresh or tinned fruit or fresh
fruit of any sort she really likes and the other stuff she’ll maybe take a bit of
maybe not…and seeing if anything else works as we’re going along, like a
trial…”(CFi201)

Marjie takes pleasure in the presence of Liz and her mother even though she no longer
recalls their names:

“when my mother comes same thing, you can see that she smiles and she you
know, knows it should be somebody that she knows, I don’t think she could say it
was mother, but she understands that it’s somebody that she knows, familiarity,
and she’ll try and touch her, mother will joke with her too.”(CFi368)

Liz relied on her belief that Marjie’s personality remains intact and therefore knew what
to do based on Marjie’s previous sense of humour. Liz believes Marjie is still the same
personality as before the AD:

“…fairly shy, but she had a really funny sense of humour, she was bright and
very funny, so she laughed quite easily, lots of things got her laughing too, like
she loved movies too like a good comedy was always good, but she was funny in
a group and always had a quick comeback for things.”(CFi92)

**Sammy and Lindsay**

Lindsay learned to ‘go with the flow’ with regard to what types of things would bring
pleasure to her father during a visit:

“…but he used to always love like anything that was food oriented like cookies
and things, and I brought him some of my homemade cookies cause he likes these
rotten chocolate chip cookies or whatever they have here, and so I brought a
homemade cookie, but my homemade cookie had very large chocolate chips in it
and it also had pieces of coconut in it and pieces of oatmeal and it was chunky,
and it was sort of getting stuck in his teeth, whereas their cookies made of like
“blah” and it melts in your mouth, so you just take a bite and it just kind of
disintegrates, my cookie had substance in it, and it bothered him like he kept
chewing and chewing and pieces of coconut going around and around in his
mouth and he didn’t really enjoy it, so here I thought he would like a homemade cookie, and so you know you just go with the flow.” (AFi452)

Family members use trial-and-error and ‘went with the flow’ when trying to elicit pleasure from the resident. Family members also drew upon some intuitive knowing that was possible due to their knowledge of their relatives’ life histories. Family members were always searching their memories for potential ways to keep bringing pleasure to their relatives. PSWs were able to learn from family members about what to do to elicit pleasure.

*PSWs knowing what to do to elicit pleasure*

The PSW interviews were tellingly shorter than the interviews with family members but all PSWs did have knowledge about pleasure. PSWs reached conclusions about whether or not pleasure is still possible. All of the PSWs talked about how their approach to care set the type of day the person would have, that is, a good versus bad start to the day. All of the staff I interviewed worked the day shift so they spoke about morning care and the importance of how the day starts for residents as a predictor of whether or not they would have enjoyable moments. PSWs showed a commitment to quality of life for the residents they cared for and they approached situations with a commitment to creating positive interactions. Positive interactions include creating moments of pleasure, joy and interest. Caregivers have a stake in wanting to create pleasure for residents because it is likely that for PSWs, happy residents make for better care recipients.

*Emma and PSW, Jane*

PSW, Jane, interpreted certain events as unpleasant for Emma. Jane mentioned that Emma sometimes has a bad start to her day when she mixes orange juice mistakenly in
her cereal bowl. Jane is usually in the dining room and assists Emma with her meal set-up to avoid this occurrence. When Emma has had a pleasant breakfast experience, she usually looks forward to participating in activities for the day. Jane describes how Emma’s mood affects whether or not it will be a ‘good day’:

“But a good day for her is when she’s up walking and dancing around and you see that she’s in a good lively mood.” (GPi87)

**Mary and PSW, Nancy**

Mary’s PSW, Nancy described how the importance of her initial approach to the day sets the tone of whether it will be a pleasurable morning or not:

“I think that, it depends on the situation, how you prepare her for the morning, how she gets up. If you make her happy she says ‘you make my day, you gave me a smile in the morning, I’m so happy’ and she’s really happy, she doesn’t like to be rushed. She doesn’t like if you tell her so many words what to do, how to do, she gets distracted right away and she gets like mad, ‘what do you want from me, go to hell!’, but if you go step-by-step, talk with her, like from the door, knock on the door, ‘good morning Mary, how are you, how did you sleep?’, she gets very nice, and I explain to her that it’s morning or it’s a nice day or Wednesday, like that.” (FPi8)

**Marjie and PSW, Theresa**

Theresa knows that Marjie’s facial expression is the best indicator of how her caregiving routines will progress. Marjie is still able to express her displeasure:

“facial expression is the main thing with her, yeah, and sometimes you see if she’s having a bad day, if she had a bad day, she won’t cooperate… yes, you tell her you know like Marjie stand up and she like you know you’re giving her care right, so okay you say Marjie do this, do this, and she goes “NO!”, she just tells you no and she just stamps her feet.”(CFi108)

**Sylvia and PSW, Abby**

I asked Abby, the PSW who worked with Sylvia, about whether she thought Sylvia could still experience pleasure, joy or happiness. Her response was the following:
“Oh yes, it depends on, she looks at you in the face, and if you’re happy, then she’s happy and mostly she responds by like laughing.” (BPi8)

“She likes company, but if you are serious then she gets worried because she looks at you, she looks at you in the face…so in the morning when you get there make sure that you are happy, or else she gets nervous and she won’t cooperate.” (BPi16)

Anne and PSW, Betty

PSW, Betty felt that having background information about Anne from her family members was helpful in planning her approach to care:

“It’s very helpful also, like when they first come here, the family will tell us what was she doing before, like when someone with her they said she was a model, so you, I correlate it with fun to dress and how we do the hair.” (EPi36)

“So I always like I said to her ‘I have nice clothes for you’ so for me I think it’s like, that is one way of like stimulating her, maybe. Maybe in her subconscious mind she is still going back to what was she before? So maybe that helps?” (EPi31)

Sammy and PSW, Violet

PSW, Violet talks about how she is able to read Sammy’s facial expression and how this foreshadows the type of day he will have:

“yeah, he says that good, I will ask him ‘did you sleep last night’ and he said ‘I slept good’ (nodding) and when there are days he didn’t sleep we can see from his face and when he’s drowsy, he’s morose, you see different expression on his face…the expression tells you a lot and the way deals with you when you do the care that itself shows that he didn’t have a good night or he was upset over something.” (APi75)

Sammy’s PSW, Violet, struggled with his personal care because of his agitation. She describes how she conceives of their relationship and how she uses certain pleasurable distracters during care:

“… my relationship with him….my relationship with him, is very, very professional, because when I he asks me to kiss him, I just put it off and I say yes, later, later, and I do my job, because with him, it’s a hard one to handle, sometimes what I’ll do I have to sing with him or dance with him, put on music, put the TV, or there are times I have to get the help of a co-worker… and I have a cordial relationship with him…
sometimes, you see, he is behavioural too, he can hit you… and at the spur of the moment you don’t know when it comes and it comes, and when it comes it’s very hard.”(API21)

Family members and PSWs know that there remains a person who is capable of experiencing momentary pleasures despite their cognitive impairment and drew upon their knowledge of the resident’s past preferences as well as using trial-and-error and ‘going with the flow’ of the day.

One resident, Sammy, who loves to socialize and exchange friendly banter no longer had the patience to sit through a gathering of old friends. He found this pleasurable for about 2 minutes and then became increasingly agitated wanting to return to his room. Thus, the source of pleasure was retained; the duration for which he could engage in this had however significantly decreased. Lindsay, his daughter, describes these changes:

“It’s a much more iffy, and you’ve got to be willing to go with the flow, and I took him out last fall one day, and I met some friends and so they knew my dad and he, you know, he was just restless, and he didn’t want to sit and talk with these people …and he just said come on, and he started to get agitated and started swearing and ‘Let’s MOVE on!!!’ (imitating his voice, agitated tone) like what are we sitting here for, and he used to like it, and so he does like it but he’s not, he can’t cope with a large group anymore, if it’s one on one or two on one or if he’s the centre of attention…”(AFi126)

The manner in which you approach Sammy sets the tone for his response:

“He responds to loving and he responds to smiling, and laughing, he loves it when people smile and laugh and are happy and are cheerful….”(AFI329)

With regard to the theme of knowing what to do to elicit pleasure, PSWs and family members reflected on their past knowledge of the person to decide what would likely elicit pleasure. Families drew upon biographical meanings (life history) whereas PSWs, understandably, lacking this, drew on their experiences working with the resident since admission to the nursing home. Some families regard themselves as intuitive ‘knowers’
while some use the “trial-an-error” approach based on knowing the resident’s past preferences.

Indicators of pleasure

All of the families and PSWs identified indicators/signals of pleasure as well as indicators of displeasure. Families and PSWs rely on observable signs of pleasure as indicators of positive affect. Indicators of pleasure included the following: facial expression, eye contact, bodily movement and gestures, non-verbal vocalization and verbalization, for example: smiling, laughing, eyes lighting up, clapping, reaching, toes tapping to music, relaxed posture, relaxed facial muscles, showing interest in certain things, holding hands, tightly grasping your hand, choosing to eat certain foods (tightly pursed lips for mashed potatoes vs. chocolate ice-cream).

Mary and Patsy

“her face lights up or she preens and she will tell you, ‘you look nice’, if you come in, if I come in and she’ll say ‘oh, your coat is beautiful’ or “that dress is lovely” or something, she still tells you.” (GFi175)

“Sleeping is a sign that she’s not interested in what’s going on.” And when asked about how she knows her mother is interested in what is happening Patsy explains:

“How do I know? Clapping, verbalizing ‘Oh that was really good, I enjoyed, that’s a really good, and he’s a really good singer” (imitating mother’s tone)...Praising the person, for their talents, she smiles, her face lights up.” (FFi99)

Patsy also told me that Mary takes pleasure in sharing verbal expressions of love with her family:

“Oh, and also I believe when you tell her how much you love her. She really likes to hear that...very much so, like every time I leave her I tell her how much I love her and that she means so much to me and then she’ll go into her response ‘oh yes, and I love you so much and I’m so happy you’re here’ and, and just she can really respond, express ...you almost want to cry because you see her, how...” (FFi245)
Patsy describes how her mother’s gait tells a story:

“… in terms of how you would see excitement exhibited in her, she would walk real fast, like to get somewhere, she’ll hoof it, she’ll be hoofing it, if she knows she’s going somewhere, and she’s excited about it. So physically, you would see that in her because she’s able to walk. And then the smile on the face.” (FFi145)

In addition, Mary maintains the ability to tell you if she is or is not enjoying herself but usually from her smiling face and quick walk, one can see her joy and anticipation to get to somewhere off the care unit. Conversely, when visits off the unit are over and family members and her private companion return home, Mary does express feelings of being lonely to the PSWs who try to engage her in conversations about her past and happy times.

*Mary and PSW, Nancy*

Mary’s PSW, Nancy comments:

“…Mary she talks sometimes about the holidays …. We will bake some cookies…and it makes her light up… like pleasure, even to talk about that, even she is always giving me some compliments and I give her some compliments. Yeah, we are sharing compliments. And she is always telling me ‘I like your smile, when you get at the door I am happy because I’m having you, I’m having you.’” (FPi50)

PSW, Nancy tells me how Mary expresses her happiness:

“And she says ‘you know why I’m doing so good? Because you are here, you are the best, you are like my family, I love you’ and she’s kissing me so many times.”(FPi35)

During my time on the unit I witnessed Mary’s expressions of affection to staff; she often used touch, holding hands and kisses on the cheek to express her happy mood.

*Anne and Emily*

Emily describes how she knows that her mother is content and happy:
“I think partly when I’m here like I make sure she’s being taken care of properly. Like when I walked in her shirt was dirty and I made, you know so she knows she’s being taken care of, you know we changed her t-shirt, we changed her jacket, I brushed her hair….I want her to be fresh and clean….a little more special…. Well by the time we left her, there’s just a little tiny smile on her face.”(EFI240)

The smile that Emily is referring to was very subtle. In fact, I had to review the videotape several times before seeing the slight change in Anne’s facial expression, which Emily recognized because of her familiarity with her mother.

Even though the words may not be understandable, the tone of the resident’s voice may be interpreted by others to understand whether it is a positive or negative emotion that is being expressed:

“…most of the time, like in the morning when the PSW goes in, my mother will be chattering, but it’s pretty much unintelligible. But I think its friendly banter from her point of view.”(EFI277)

Residents with advanced impairment who cannot talk can still communicate their food preferences. Anne does so by choosing whether or not she likes the taste of what is being fed to her at mealtime:

“Now she will usually let you know if she’s enjoying the food or not because she won’t open her mouth if she doesn’t want it. And she’s getting more difficult to feed. Now applesauce seems to be one of her favourite things lately and she will open her mouth for apple sauce and she will get.”(EFI340)

Family members described subtle indicators of pleasure and enjoyment in their relative:

“Cause she could be sitting at a concert with her head slumped over and sort of snoozing…well, she might be asleep and then all of a sudden she might seem more alert, her eyes might still be closed, but you are aware that she’s participating in the event. Her toe might be tapping. Her face might be a little, kind of the way it was before. Its kind of a little beautific smile, it’s not like a big smile, it’s just that little smile that you think okay she’s having an okay time, and it’s sometimes very subtle like that. It isn’t necessarily opening eyes, that big smile, she does do that occasionally, but it’s more and more rare.”(EFI409)
Emily focused on her mother’s posture to indicate how she was feeling and whether or not she was enjoying something. Emily described Anne as enjoying quiet solitude in her pre-Alzheimer’s state so Anne may maintain some of that need for alone-time. Emily said:

“If she is left in the public areas, she would be more, I can’t even do it, but like slumped over, with no expression on her face. She doesn’t like to be in the lounge and by the nursing station. She was also, like she had great relationships with her friends and her family, but she was also a solitary person like she might take that two hour or three hour walk by herself. So she enjoyed spending time by herself.” (EFi251)

Anne and PSW, Betty

PSW, Betty talked about her morning feeding routine with Anne and the indicators of pleasure she relies on seeing:

“…whenever I talk to her like during the meal time in the morning, during breakfast time, I try to talk to her especially when she is alert and when her eyes open and she starts talking and just like this morning I was feeding her and at the same time I was talking to her, like ‘do you like the taste of your food?’ and then before I give the food to her, I said to her like ‘I have here the banana and try it’ and she opened her mouth and you can see from her face that she is smiling and ‘how you like it?’, ‘mmmm’ she just says that.” (EPi16)

Betty describes the indicators of pleasure for Anne:

“She doesn’t really express it verbally but sometimes she smile, so, and that’s a key where she enjoys what you’re doing to her. And also the touch is number one because they know that if you touch them, like gentle touch, they can feel it.” (EPi42)

Betty can no longer understand Anne’s verbal expressions, but she gives an example of how she is able to interpret Anne’s preference to continue eating; eating was also thought to be a pleasurable activity for Anne from Anne’s daughter’s perspective:

“Okay we go back to the feeding again breakfast like in the morning, so she’s there and I held up the head and I’m sitting beside her and she was holding my hand and whenever I want to reach something, and she thought that I am leaving, so she grabbed me! I’m like ‘no, no Anne, I’m not leaving you, I’m still here, you’re not done yet, you have to finish your food yet’…and then, and also I say ‘Anne do you like me?’ and she say “mmmm mmm”… also it has to do with her
condition, you don’t really know. But she talks a lot but you don’t know what… mumbling or sometimes there’s also words, like ‘that man is..’ something, and I say to her ‘yes’, but I don’t know, there’s no sense, but then still, I say, ‘Oh you’re smart Anne’ and then she say ‘well’.” (EPi66)

*Marjie and PSW, Theresa*

Theresa, Marjie’s PSW gives an example of an indicator of pleasure:

> “you can notice like when she doesn’t see her husband for a few days like, you know she looks so sad and withdrawn, but the moment her husband walks in or she sees her husband, her light just, eyes just lit up and you know, she’s so happy and she’s just rubbing and stroking his hair.” (CPi10)

*Sammy and PSW, Violet*

PSW, Violet talked about the things that elicit pleasure in Sammy:

> “singing, he likes singing, when you sing with him, he’s happy…like he doesn’t sing with you, but he’ll make noise like babies make ‘la, la, la’, but he’s happy, so I usually put on music for him, or a TV movie, it helps him to be happy. He likes food, he never makes a fuss over food, he likes food, and he enjoys it.” (APi94)

*Isa and PSW, Alice*

The exception to the responses from PSWs who were interviewed was Alice. Alice found it challenging to see positive emotions from Isa:

> “sometimes when she’s in the dining room, like when you are, before you feed her sometimes you talk to her, sometimes she is responding, sometimes nothing at all…. She’s just sitting there and completely gone, she doesn’t communicate.” (Dpi44)

Both family members and PSWs described indicators of pleasure aside from PSW, Alice. Examples of observable signs of pleasure as indicators/signals of positive affect include: smiling, laughing, eyes lighting up, toes tapping to music, relaxed posture, increased pace of walking, relaxed facial muscles, showing interest in certain things, holding hands, tightly grasping, choosing to eat certain foods.
Continuity of Personality

I asked family members to tell me about their relative’s personality and how it may or may not have changed. Consistently across the cases all family members said that personality in the resident was maintained/stable from pre-illness. Any changes in personality they saw were described as disease related and manifested in behaviours associated with agitation. Interestingly, even though Sylvia is euphoric, her daughter did not describe her personality as different. Perhaps Ivy was separating the disease process from the person her mother is.

Sammy

Lindsay describes her father’s personality as jovial and down-to-earth:

“very, very congenial, very OVERLY friendly liked everybody, got along with everybody, he was a placater, you know a conciliator kind of person, if two different people were having fights, my dad would resolve everything and everybody would get along and that was how he managed so many different conferences, because he just got along with everybody and you could be like an important politician or you could be a gas station attendant or you could be a cook in a hotel and he would mingle with whoever he, he didn’t put on airs, he was always a very, very friendly kind of a guy and am, just a good sense of humour, he always joked around and that, and he STILL has a sense of humour. He always joked around, he used to make bad puns all the time and he used to joke around, and he always had a twinkle in his eye…”(AFi292)

Mary

Patsy described Mary’s personality as outgoing before and even after her Alzheimer’s disease:

“before, pre-Alzheimer, I would say she was pretty extraverted, opinionated, personality wise, and I would say she is [still] pretty extraverted.”(FFi25)
Anne

Anne continued to prefer to be alone and valued her privacy:

“If she is left in the public areas, she would be more, I can’t even do it, but like slumped over, with no expression on her face. She doesn’t like to be in the lounge and by the nursing station. She was also, like she had great relationships with her friends and her family, but she was also a solitary person like she might take that two hour or three hour walk by herself. So she enjoyed spending time by herself.” (EFi251)

Marjie

Liz believes Marjie is still the same personality as before the AD:

Liz: “fairly shy, but she had a really funny sense of humour, she was bright and very funny, so she laughed quite easily, lots of things got her laughing too, like she loved movies too like a good comedy was always good, but she was funny in a group am and always had a quick comeback for things.

Malini: “and do you seen any of that personality now?”

Liz: “Sometimes, I will still see her laughing sometimes, when I make some joke about things she would like that. When she was a very little girl, probably now when she’s an older girl, she used to hate liver and on nights when my mother would make liver, Marjie would start crying in the afternoon (laughs). So last week, [her companion] and I took her downstairs and I got her a chocolate cookie, because I know she likes chocolate, and I was kidding [her companion] and I said it’s a good thing it’s not a liver cookie cause Marjie would start crying and Marjie started laughing cause she remembered that she didn’t like liver. Or the same with washing her hair she’d just scream cause she hated having her hair washed, and so when she first came here and the nurses were struggling with her to get her hair washed, and she’d just be having a royal fit.” (CFi92)

Sylvia

Ivy described Sylvia as maintaining her pre-illness personality:

“I think she was an outgoing personable person” (BFi192)

“And at this stage in our lives it’s kind of role reversal, I’m caring for her now and am she, AND I must say that her character is such that she is not one to... she doesn’t cling, she’s, she’s happy to see me, and if it gets too intense and I want her to eat more or drink more she’ll say, “well it’s, time to go, time to go” (imitates mothers voice) (BFi101)

The continuity of personality importantly exhibited by all of the residents helped family members to enhance quality of life of residents beyond basic needs. Family members attributed changes in personality such as episodic agitation and euphoria to the
disease process. In the higher functioning residents including Marjie, Mary and Sammy, family members could integrate reminiscence and early memories to bring about pleasure. Family members could tap their early memories and trigger a laugh or smile from the resident whereas PSWs must rely on information from family members in order to understand the resident’s past personality.
CHAPTER 7: DISCUSSION

Introduction

The purpose of this study is to understand what creates pleasure in the daily lives of people with advanced dementia of the Alzheimer type (DAT) living in residential long-term care settings. This study examined four research questions. The first three questions focused on the family members’ perspective since it was not possible for residents to provide this information. The first research question addressed how family members create pleasurable experiences for their relative who is cognitively impaired. The second question examined how they draw on biographical meaning in creating these experiences. The third elicited information about what indicators they use to determine whether their relative is content, interested or experiencing pleasure. The fourth research question asked what happens when PSWs try to replicate the pleasure-inducing activities and interactions that family members use with the resident.

Family members described their struggle to decipher what sources of pleasure remained for their relative. In the residents with very advanced dementia, family members had to impute or attribute meaning about their relative’s inner state (mood or emotion) using their knowledge, sometimes guessing and reflecting on the person’s past. The resident’s life story, significant life events, previous personality and current state were part of the family members’ considerations when discussing pleasure in their relative. PSWs also used their more immediate knowledge of the person with dementia usually derived from personal experience as a basis to interpret meaning and act accordingly. The discussion of the results that follows will first address the family
members’ struggle, second examine the PSWs’ knowledge and finally interpret the concept of pleasure in advanced dementia.

*Family members’ struggle*

The answer to the research questions about how family members create pleasure and whether they draw on biographical meanings in deciding what to do during visits with their relative involved the dominant theme of their struggle to figure out the answers. All family members struggled to decide what to do with their relatives with dementia during their visits to the nursing home. The five daughters, Susie, Patsy, Emily, Ivy and Lindsay, the one sister, Liz and one husband, George all described how they were dealing with lost abilities. In moving their thoughts between lost abilities and determining what to do during their visitation to the nursing home, the sheer exhaustion of searching for retained sources of pleasure was made clear. The exhausting work of caregiving for people with dementia in their own homes is well documented and the strain and burden (physical, emotional and financial) on the part of family members may culminate with institutionalization (Ducharme et al., 2007; Lee & Cameron, 2004; Neufeld & Harrison, 2003; Ory et al., 1999; Parks & Novielli, 2000; Pearlin, Mullan, Semple & Skaff, 1990; Zarit, Todd & Zarit, 1986). The complex sociological model of the caregivers’ stress process developed by Pearlin and his colleagues suggests primary objective stressors are those directly related to the care recipient’s behaviour (frequency of behavioural disturbances) and functional status (level of dependence with ADLs). Primary subjective stressors flow directly from the primary objective stressors and include role overload, role captivity and relational deprivation (Pearlin et al.). Secondary stressors apart from the caregiver-care recipient relationship are in the broader context of family relations (Pearlin
et al.). This model of caregiver stress outlines the various sources of stress and the potential for mediators such as social support from formal and informal sources in helping caregivers to cope.

Gaugler, Anderson, Zarit, and Pearlin (2004) applied the stress process model described above to examine the long-term transition to nursing home placement. They found that the frequency of visits by family was negatively related to post-placement role overload for family caregivers, i.e., family members that visit frequently have less role overload (Gaugler et al.). Reasons for this reduction of stress from that usually during in home caregiving was thought to be related to the care provided by the nursing home (NH) staff,

…care provided by NH staff may have freed family caregivers from emotionally and physically draining tasks, such as toileting and bathing. The provision of intensive, ‘technical’ hands-on care by staff may have also allowed family members to pursue the more fulfilling aspects of their roles during visits, such as socializing and sharing meals. On account of this shift, visits could have become more enjoyable as family caregivers assumed the traditional aspects of their roles as daughter, son, spouse, or relative (Gaugler et al., p. 72).

Further, Gaugler et al. described the care that family caregivers gave as “preservative” or “help that is based on maintaining the identity, humanity, preferences, and quality of life of the institutionalized loved one” once they no longer felt the stress of providing supervision and ensuring safety of their relative (p. 73).

While some research has found that the caregiver stress following institutionalization is decreased (Gaugler et al., 2004), family members who remain involved in care and who visit regularly take on another type of responsibility with regard
to care. Family members’ goal of keeping the individuality of their relative alive resonates with the concept of selfhood. Selfhood is expressed through personal identity including the manifestation of past roles and personae (Sabat, 2001). Family members factored the resident’s past roles and personae into decisions about what may constitute a positive interaction. Reflecting on what they did during visits, families identified lost, retained and new sources of pleasure. The work of creating pleasure was evident when families described using a trial-and-error approach. Their interpretation of what they did that created pleasure depended on whether or not their relative appeared somehow to enjoy the particular activity. If the activity was not deemed to be enjoyable, it was stopped and another potentially pleasurable interaction ensued.

Phinney (2006) found that three strategies were used by families of community dwelling persons with mild to moderate dementia to help them maintain involvement in meaningful activity: reducing demands, guiding, and accompanying. All of these strategies were seen in some of the cases in this study. For example, Mary, who had moderate dementia, benefited from reduced demands and required guidance during activities, but others like Emma did not retain the abilities necessary to understand guidance from her caregivers. Phinney described examples where accompanying occurred with family members “staying alongside the individual as he or she engaged in everyday activities” or seeking new activities that they could engage in together (p. 92). Emma’s PSW, Jane, described having Emma accompany her for walks off the unit; for example, when Jane needed to go off the unit for certain tasks, she would take Emma along for a walk. Marjie also accompanied her PSW, Teresa, for walks off the unit.
There are two theoretical ways of explaining the behaviours exhibited by people with AD; one is the theory of retained abilities (Dawson, Wells & Kline, 1993) and the other is the theory of retrogenesis (Reisberg et al., 2002). Dawson’s and her colleagues’ theory of abilities-focused care based on minimizing excess disability (the undue loss of abilities imposed by environmental factors rather than actual disease) through supporting the resident’s remaining abilities is suggestive of Phinney’s (2006) strategies of reducing demands, guiding and accompanying. Another study that examined spousal caregiving also found “supporting competencies” occurred through recognizing retained abilities and cueing and supporting the partner to utilize those abilities (Perry & O’Connor, 2002, p. 57). Susie initiated the card playing with Emma and guided her through a mock game of cards to the extent that was possible given Emma’s remaining but increasingly limited ability to engage in card playing. Patsy also maximized her visits with regard to pleasurable interactions by focusing on Mary’s abilities to maintain a simple conversation and to socialize with other residents off the care unit. The results of this study are consistent with an abilities focused care perspective and with Phinney’s model of involvement in meaningful activity for residents in the moderate stage of DAT. However, when a person has severe dementia as Anne and Isa have, these strategies are less applicable.

Anne’s and Isa’s total dependence for all ADLs meant that instead of supporting remaining abilities, they required total care in all aspects of living. Visiting relatives with advanced Alzheimer’s disease is difficult as family members are faced with a parent, spouse or sibling who no longer recognizes them (Li & Orleans, 2002) and for whom the strategies of guiding and accompanying no longer work to create meaningful interactions.
These families are required to dig deep in their reservoirs of biographical knowledge and creative problem solving to come up with strategies – which they do. Families do not stop visiting. There was a strong commitment to caring for the residents by all families in this study. These family members felt that pleasure was still possible, but it was a process of trial-and-error mixed with intuition about knowing what might work based on their knowledge of the resident’s past that they used to determine what to do during their visits. Families described lost pleasures largely based on reflecting back on biographical meanings or the person’s life history. Dancing was a source of retained pleasure for Emma and Marjie. Palo-Bengston and Ekman (2002) examined the emotional response to social dancing and walks in people with dementia and concluded that people with dementia should be given the opportunity at musical events to dance because their bodily movements are a way of articulating emotions.

Retained pleasures were what the person enjoyed pre-illness and continues to enjoy. Three key retained pleasures for most of the residents with advanced dementia are touch, music and food, especially sweets. There is mounting research evidence that musical recognition is spared in dementia (Cuddy & Duffin, 2004). Both the recognition of music and the enjoyment derived from it are thought to be spared in some people with dementia (Norberg, Melin & Asplund, 2003; Sherratt, Thornton, & Hatton, 2004). Of the various tastes, sweet is the only innate taste, for all of the others are acquired tastes. Interestingly, childhood studies have found that “neonates seem to have an innate preference for sweet tastes” (Crook, 1978 as cited in Harris, 1997, p. 17). However just as in normal aging, in dementia there are also some changes with taste. Lang et al. (2006) conducted an exploratory study on taste in dementing diseases and reported that there is
“a mild reduction of gustatory function in dementing diseases over and beyond that of normal aging” (p. 177). Touch was another sensory pleasure that was described in several of the case studies. Touch ranged from hand holding, to tightly grasping to gently stroking an arm during mealtime. Massage and touch have been described as therapeutic in the management of agitated behaviour, anxiety and depression in dementia (Viggo Hansen, Jorgensen & Ortenblad, 2007). Therefore it may be reasonable to suggest that all care providers, professional and familial, should use various types of touch, continue to provide music that was enjoyed and give sweets that persons with advanced dementia in their care are known to enjoy as ways of bringing pleasure.

The second way of explaining these retained pleasures lies in the theory of retrogenesis that is defined as “the process by which degenerative mechanisms reverse the order of acquisition in normal development” (Reisberg et al., 2002, p. 202) (Appendix J). Reisberg and colleagues (2002) claim that if people with DAT were understood using the retrogenesis model, appropriate and sophisticated principles of care would be possible. The retrogenic process model provides a developmental age for each corresponding stage of AD based on the Functional Assessment Staging Test (FAST) (Reisberg et al., 2002). Using this model, all of the participants in this study would be in a developmental age of 15 months to 5 years of normal development (See Appendix J, K). Table 1a outlines the pleasurable activities that residents demonstrated during the video-recording sessions.

Stage six of the FAST corresponds to the developmental age from approximately two to five years, meaning that functionally the abilities of the person with AD to dress and bathe independently are limited and later on their ability to toilet themselves is also compromised with incontinence often occurring (Reisberg, Kenowsky, Franssen, Auer &
Souren, 1999; Reisberg et al., 2002). According to the theory of retrogenesis an adult in stage six of the FAST requires the same level of assistance with ADLs and supervision that a two to five year old child would require (Reisberg et al., 1999). Stage seven of the FAST corresponds to a developmental age from early infancy to about one and a half years where people with AD are doubly incontinent, inarticulate verbally, are unable to ambulate or sit up independently, to smile, and in the end stages to hold up their heads independently, thus requiring the same amount of care as an infant (Reisberg et al., 1999).

The two people with the most advanced dementia were Anne and Isa – both are in stage seven of the FAST (see Appendix K). Empathic verbal conversation was used by Anne’s daughter and Isa’s husband when communicating with them. According to Reisberg et al. (1999) this empathic verbal dialogue is similar to what mothers use with their infants to interpret the infant’s facial expressions and nonsensical verbalizations. Such verbal interaction appeared to be intuitively employed by family members and PSWs when communicating with the residents in this study.

The theory of retrogenesis (Reisberg et al., 1999; 2002) relates the stage of AD with a developmental age, but, retrogenesis theory itself does not help one to know what may be pleasurable in a particular person with AD. Reisberg et al. (2002) acknowledge that there are caveats to the retrogenesis model. For example, one caveat is that while infant development is marked by increasing expectations, progression of AD is met with decreasing expectations (p. 209). One of the most significant problems with the retrogenesis model is that while infants cannot draw upon previously mastered knowledge, people with AD do to some extent have access to previously learned skills (p. 209). Intervention studies examining Montessori-based Dementia Care Programming©
capitalize on the remaining procedural memory and use spaced retrieval in people with mild to moderate dementia (Camp, 2001; Malone & Camp, 2007). Therefore, it is probably limiting to only offer the things that are appropriate to a certain developmental age without knowing what the individual enjoyed in the past. Additionally there is a risk of infantilization and providing undignified care if elders are treated like children of a certain developmental age. This risk may outweigh the benefit of correlating a FAST stage with the most appropriate care. In fact, an abilities focused care paradigm (Dawson, Wells & Kline, 1993) may achieve the same results in terms of knowing what stage of disease the person is living through and what their potential repertoire of abilities is. Caregivers can capitalize on a person’s retained abilities and use appropriate cues to elicit preserved procedural memory.

Family members are a source of knowledge about the person’s current pleasures. Determining what to do with the person is exhausting work as it requires constant reassessment. Not only do family members have to continuously adapt to lost abilities but they also have to engage in a day-to-day trial-and-error process to decide what to do with their relative during visits. In general, they used strategies that worked for periods of time until there was another change in the disease process which negated doing certain things; often with diminished abilities there are fewer things available for family members to do during visits. For example, Anne’s daughter, Emily described how when her mother first moved into the facility they used to go for walks and spend more time in the public areas of the home, whereas now she can no longer take Anne for a walk without the help of a physiotherapist and they spend all their time in Anne’s room instead of in the public spaces of the nursing home. Similarly, Sammy’s daughter, Lindsay described how
telephone conversations are no longer possible with her father. This was one way that Lindsay, who lives out of town, used to be able to maintain contact with her father on a daily basis. Instead of telephone conversations with his daughter, Sammy, now engages in mostly verbal exchanges with his private caregiver who spends one-to-one time with him during the day and with his PSWs during personal care routines in the morning and evening. Sammy maintains the ability to socialize but the nature of the socialization varies throughout the day. For example, if he is having a good day, he shows signs of enjoyment when going for a stroll off the unit and seeing other residents. This very same outing proves to be agitating at other times. Therefore, caregivers must make decisions in the moment depending on his response about whether a particular activity or interaction is pleasing to Sammy or not.

The first two research questions aimed to answer the question asked: How do family members create pleasurable experiences for their relative who is cognitively impaired and how do they draw on biographical meaning in creating these experiences? Family members in all seven of the case studies expressed their commitment to their relative living with dementia. Despite all of the losses associated with dementia, families were not dissuaded, they visited often. They would strive to create pleasurable experiences during their visits by attributing meaning to the responses given by their relative during various activities or interactions. They decided whether sources of pleasure were lost, retained or new based on their knowledge of their relative’s past preferences and lifestyle thereby drawing upon biographical meanings and the overall context of life history. This is an exhausting process that demands trial-and-error be employed in order to decipher which strategies are successful and result in a positive
response from the person with dementia. Their goal is to sustain selfhood by encouraging participation in familiar things.

The process of trial-and-error decision making engaged in by these family members may be most usefully explained by the theory of retained abilities (Dawson, Wells, & Kline, 1993) as well as Phinney’s (2006) strategies. Both contribute to furthering our understanding of the scope of abilities which the person with dementia may be capable of. The retained abilities and strategies used by family members inform decisions about what to do during the visit and indicate what may bring about a smile, laugh, or some other indicator of pleasure.

*What do PSWs do to create pleasure?*

The fourth research question asked: What happens when PSWs try to replicate the pleasure-inducing activities/interactions that family members use with the resident? Three things stand out when trying to answer this question. Firstly, several of the PSWs chose not to replicate what the family members had done to create pleasure but rather demonstrated their own strategies. Secondly, the PSWs of the two residents with the most advanced dementia did replicate the family members’ approaches although they added their own twists, and thirdly, all PSWs knew how to create pleasure as it was defined.

PSW training is briefly described followed by several other perspectives on what guides PSW work. The curriculum to prepare Personal Support Workers (PSW) was approved and began in Ontario in 1997 replacing the previous Home Support Workers Level II and III and Health Care Aide and Personal Attendant training programs (Ontario Ministry of Health, Long-term Care Division, 1997). PSW training programs in community colleges in Ontario are usually offered over two terms or eight months in
which an average of 384 hours are spent learning theory in classrooms and about 386 hours are spent on practical experience for a total of 770 program hours (Health Professions Regulatory Advisory Council, 2006, p. 20). Programs at private colleges usually average 540 to 640 hours in total (Health Professions Regulatory Advisory Council). In long-term care settings, PSWs carry out personal care including dressing, personal hygiene, mobility and other routine activities of living. There are no current data collected on the actual number of PSWs working in Ontario because PSWs are an unregulated profession but Health Canada estimates there are about 100,000 in Ontario (Health Professions Regulatory Advisory Council) of which about 57,000 are working in long-term care institutions (D. Hughes, personal communication, March 4, 2008). The staffing ratio in the facility where this study’s data were collected was six residents to one PSW during day shifts; nine residents to one PSW during evening shifts and 18 residents to one PSW during night shifts (Director of Nursing, personal communication, November 18, 2004). This background information about the status of PSW training and education along with staffing ratios at the facility is given in order to provide the context in which PSWs work and are trained. The PSWs who participated in this study had many years of experience beyond their basic training.

Liaschenko and Fisher (1999) described four types of knowledge: case, patient person and social knowledge. In their theoretical model, social knowledge links case to patient knowledge and patient to person knowledge (Liaschenko & Fisher). Case knowledge refers to “general knowledge of pathophysiology, disease processes, pharmacology, and other therapeutic protocols” (p. 29) and patient knowledge,
includes knowledge of how an individual becomes identified as a patient, knowledge of the individual’s response to treatment, knowledge of how to get things done for the individual within and between institutions, and knowledge of the many others who are involved in providing services across time and space (Liaschenko & Fisher, p. 35).

Case and patient knowledge are critical to RNs. Person knowledge and social knowledge although focused on RNs not PSWs, nevertheless seem highly relevant to the latter. They identified that “person knowledge” was a strong reminder that the life of the recipient of care was meaningful and would help in defending certain courses of disease management and actions. Similarly, one may infer that in long term-care, knowledge of the person with dementia facilitates action. Liaschenko’s and Fisher’s concept of “social knowledge” includes knowledge of social living conditions, the impact of the person’s diagnosis on his/her functioning and ability to manage in certain contexts, the predominant views about the disease and the individual’s own view of his or her disease. Several aspects of social knowledge bear upon the PSWs who work in long-term care. For example, social knowledge may be important for the early stages of cognitive impairment following the diagnosis when the person is still living at home in a community context. However, in an institutional setting when the disease has progressed to an advanced stage the person with DAT can no longer tell us what having DAT means, consequently, social knowledge is difficult to assess in the absence of subjective accounts from the person with dementia.

It was social knowledge and person knowledge that PSWs drew upon when responding to interview questions about what they do to create pleasure and in
demonstrating what they believed to be pleasurable. PSWs considered two things when deciding what to do: who the person was and what their past preferences were. In addition, the context of each situation and the resident’s response determined how the caregiving would proceed. It may be that the PSWs’ tenure and levels of expertise in long-term care and their long standing relationship with the residents contributed to them choosing not to replicate what family members demonstrated but instead to demonstrate their own expertise. Perhaps a more novice PSW would have taken guidance from the family member’s video recording in order to know what worked well with the resident to bring about a positive interaction.

Several authors have examined PSWs’ work from different perspectives, including nursing home ethnographies by Henderson (1994) and Diamond (1992), and Janes’ (2006) grounded theory study. Henderson examined the work of certified nursing aides (CNA) in nursing homes while working for 13 months as a CNA. Using two case study exemplars, Henderson described unofficial work of CNAs including making “folk diagnoses”, particularly related to skin integrity and bowel habits and discovering that “each aide had memorized a huge array of personal habits of each patient – a stratagem that rendered service to the patient not only more efficient but also more personal” (p. 21). Henderson concludes that CNAs are a potentially useful resource for nursing and medical staff in nursing homes because they compensate for their limited training by relying on “surrogate kinship roles, a thorough familiarity with the patient, and the use of folk therapies” (p. 22). Therefore, the ability of PSWs to demonstrate a unique interaction by not replicating the family member’s interaction seen on the videos may also be attributable to their awareness of personal preferences in the residents they worked with.
Qualitative methods including narrative inquiry and ethnography have been used to gain an understanding of the context of health care aides’ work demonstrating engagement with residents despite issues about gender, marginalization and quality of worklife (Diamond, 1992; Henderson & Vesperi, 1995). Diamond, a sociologist, underwent nursing assistant (equivalent to health care aide) training, worked in a nursing home in the early 1980s and reported on his insider perspective of routines in long-term care. Through participant observations he documented the physically exhaustive work and emotionally heart wrenching stories of the nursing assistants while acknowledging their strength and use of “mother’s wit” in returning to the daily grind day after day. According to Diamond, “mother’s wit” is a blend of caretaking skills nursing assistants have learned with their own families, common sense, and awareness of the needs of another person. While Diamond did not document dementia specific care units, the work that PSWs do in long-term care appears to be driven by a deep commitment to dignified and respectful care. Other researchers have studied group homes for people with dementia in Sweden and found the metaphor of “maternal love” to be relevant in understanding the thinking processes employed in optimal care for people with dementia (Haggstrom & Norberg, 1996).

Emma’s PSW echoed this idea of “mother’s wit,” when describing to me how she knows what to do with Emma to bring about a positive mood including the perspective that it is essential to treat the residents in the same way that she herself would want to be treated. Evidently, she was drawing on her awareness of what she or her own family members may want were they in a dependent care situation such as Emma’s. All of the
PSWs talked about the idea of common sense along with attention to needs as the factors that help them to know what to do with the residents.

Whereas Henderson (1994) and Diamond (1992) describe the folk aspect of nursing aide work, Janes' (2006) work moves beyond ideas such as “mother’s wit” to describe the PSWs’ scope of practice related to problem solving. Janes conducted a grounded theory study to examine how PSWs use person-centered work and theorized that PSWs working in long-term care rely on “figuring it out in the moment”. The PSWs in this study were not asked to articulate how they knew what to do, but did describe the importance of approaching the resident in an appropriate manner and being flexible to each individual’s unique situation. Residents have both good and bad days and this influenced how PSWs introduced pleasurable activities. The way that PSWs approached each day was with a certain amount of certainty about how to provide ADL care, but also with a level of uncertainty about how well the resident had slept, or whether or not they were in pain or not feeling well. For example, Sylvia was prone to urinary tract infections and if she was feeling unwell, the PSW would alter the course of her day to provide comfort. With Sammy, morning care set the tone for the rest of his day; if morning care was fraught with agitation, that negative emotion appeared to be carried over to breakfast and the rest of the morning. Perhaps it was a combination of “figuring it out in the moment” using their previously acquired knowledge about the resident that helped PSWs to provide pleasurable interactions throughout the day.

Whether one is a novice or an expert practitioner, dealing with aggressive behaviours is challenging. Aggressive behaviours stood out in case study seven which demonstrated a type of caregiver abuse between Sammy and Violet. A study by Holst,
Edberg and Hallberg (1999) reported on nurses’ reflections on caring for persons with severe dementia. These authors identified several theme defining encounters. For example, “encounters characterized as an encroachment on identity” for verbally and physically aggressive behaviour where nurses wanting to be a “good nurse” felt uncertain about how to deal with the situation while maintaining their professional identity (Holst, Edberg & Hallberg, p. 94). Another interpretation of aggressive behaviour is offered by Egan et al. (2007) who studied the impact of life history knowledge on aggressive residents. They found that life history knowledge impacted positively caregiver’s interactions with aggressive residents (Egan et al.). Similarly, PSW Violet, used her knowledge of Sammy’s life history, in particular his previous career, to distract him during his sexual advances. For example when Sammy was asking her for a hug, she began talking about the work he once did and engaged him in a conversation about that instead. Such distractions worked for the moment until he was once again asking her to dance with him or pulling her by the arm to be closer to him. Violet’s daily struggle with an overtly sexual resident with AD did not, however, prevent her from engaging with him in a positive manner. She described how reminiscing and singing were two things that she did with Sammy to bring about pleasure in his day. By compartmentalizing the negative behaviour in the “disease” domain Sammy remained a good person deserving of optimal care provision by Violet.

The severely withdrawn resident presented a challenge when it came to understanding how to create pleasure. Case studies three and four also stood out because these were the most withdrawn residents with the least number of sources of pleasure. Holst, Edberg & Hallberg (1999) identified “encounters characterized by non-
understanding and vague identity” for the withdrawn severely impaired residents (p. 95).

Residents such as Anne and Isa who give hardly any response have been shown to create a sense of uncertainty in nurses who find it difficult to know whether or not they are responding and acting in a way the resident wants (Holst, Edberg & Hallberg). However, through interpretation based on non-verbal communication many situations are navigated successfully and meaning may be imputed to behaviours. PSWs engage in this type of navigation daily but there was not always consensus on the interpretation. The subtle upturning of Anne’s lip that was interpreted as a “smile” by her daughter Emily was not readily apparent to her PSW nor to me. I could not see what Emily saw even with repeated viewings of the time segment in the video that captured this facial expression which Emily thought was an indicator of pleasure in Anne. Abby, Anne’s PSW focused on having Anne open her eyes. For Abby, eye contact was the important indicator of Anne’s level of enjoyment. Anne had a downward gaze and did not open her eyes during my observations. Abby continuously asked her to do so during breakfast perhaps checking to see if Anne could still make eye contact. The daily work of PSWs in long-term care is both physically and emotionally exhausting (Diamond, 1992; Foner, 1997). It has been said that “until the physical, emotional, and intellectual components of nursing work are formally acknowledged and valued, programs in long-term care will continue to be geared toward instrumental task maintenance” (Ward-Griffin & McKeever, 2000, p. 100). PSWs were clearly not merely focused on ADL care and task maintenance, but truly worked to engage with the residents they worked with day in and day out and to create pleasure when the opportunities presented themselves.
The level of knowledge about the person that PSWs possess has not been recognized in the literature and family members have been regarded as the experts in knowing their relative. However, building on Janes’ (2006) grounded theory about PSWs’ ability to problem solve and figure out effective ways of providing person-centred care, this study also found evidence that PSWs are knowledgeable about what creates pleasure in persons with moderately severe to severe dementia. They chose to replicate family members’ approaches when they concurred with them and chose not to when they had a repertoire of things that worked well to bring about pleasure that were different from the family member’s interaction. The PSWs who chose not to replicate the video-taped interaction between the family member and the resident not only demonstrated that they have their own unique ways of interacting with residents but also that they had figured out what works with the resident. Some PSWs may have replicated the exact interaction because they did the same thing (especially relevant with Anne and Isa whose ability to experience pleasure was limited to basic sensory interactions) or may have chosen to replicate the interaction because I asked them to do so. Those who chose not to may have simply had different ways of interacting and not been at ease trying out something new or felt it inappropriate for them to do the same thing.

The concept of pleasure

The overall purpose of this study was to understand what creates pleasure in the lives of people with advanced dementia living in a long-term care facility. While none of the research questions asked about the concept of pleasure directly, the relevance of this concept for people with advanced and very advanced dementia emerged as important in analyzing the interviews and video-recorded data. Therefore, the following section will
discuss the concept of pleasure in dementia and will suggest that the concept of pleasure is not relevant in individuals with severe dementia but the concept of connecting is, given there are no observable indicators of pleasure remaining when a person stops smiling, laughing or showing any observable signs and gestures associated with pleasure.

The concept of pleasure is important to dementia care for people in the early to middle stages because it is a positive emotion that indicates to caregivers whether or not their interventions and interactions are having a positive impact on the resident. Aside from the literature on the perception of emotions (Allen & Brosogle, 1993; Brosogle, Kurucz, Planhovinsak & Gumiela, 1981; Brosogle, Kurucz, Plahovinsak, Sprotte & Haveliwal, 1983; Luzzi, Piccirilli & Provinciali, 2007) and the function of the amygdala in processing emotional stimuli (Adolphs, 2002; Suslow et al., 2006), it was established in the review of the literature that there is a paucity of information about the concept of pleasure in people with dementia. However, the importance of detecting the presence of pleasure in the daily lives of residents with dementia in order to ensure opportunities are created continues to be relevant as demonstrated by the efforts of family and staff.

In general, pleasure is a feeling (attitudinal pleasure) or sensation (sensory pleasure) that is caused by an “episode” that varies in both duration (period of time) and intensity (“strength or vividness”) (Feldman, 2004). Low intensity or high intensity may not be conveyed by the person (Feldman). More specifically, positive affect in people with dementia of the Alzheimer type is defined as a subjective pleasurable, interested or contented feeling perceived by the individual that may result from an external antecedent stimulus or an internal memory (Labouvie-Vief & Medler, 2002; Lawton, Kleban, Rajagopal & Dean, 1992; Lawton, Van Haitsma & Klapper, 1996; Pankseep, 1998).
Intensely positive emotions are connoted by descriptions like “joyful” or “spirited” and less intense positive emotions are described as “pleasant and mellow” (Tappen & Williams, 1998). A full range of positive emotions was observed in the video recordings in five of the seven case studies. For example, Sylvia was overtly joyful and spirited in her interactions as was Sammy, whereas Marjie and Emma were more pleasant and mellow in their video-recorded interactions with both family and PSWs.

Researchers in the field of psychology have examined the structure of mood based on self-report data in the general population (Lawton, Kleban, Rajagopal, & Dean, 1992; Watson, Clark & Tellegen, 1988). According to Watson, Clark and Tellegen,

Positive affect (PA) reflects the extent to which a person feels enthusiastic, active and alert. High PA is a state of high energy, full concentration, and pleasurable engagement, whereas low PA is characterized by sadness and lethargy. In contrast, Negative Affect (NA) is a general dimension of subjective distress and unpleasurable engagement that subsumes a variety of aversive mood states, including anger, contempt, disgust, guilt, fear, and nervousness, with low NA being a state of calmness and serenity… PA – but not NA – is related to social activity and satisfaction and to the frequency of pleasant events. (p. 1063)

Indicators of positive affect contained in Lawton et al.’s (1996) Apparent Affect Rating Scale (developed for people with dementia) were seen in people with moderately severe dementia. Five of the seven participants in this research study displayed positive affective facial expressions including smiling and making eye contact and bodily gestures including nodding, gesturing and tapping feet to music. In people with moderately severe dementia such as Emma, Marjie, and Sammy, observable indicators of enjoyment including happy facial expressions were present during my visits and during the video recorded interactions with family members and PSWs. Sylvia, being euphoric, was elated
all the time during the observations. Mary had retained more functional and communicative abilities than all of the participants and could answer questions related to whether or not she felt happy, excited, unhappy or dissatisfied.

Indicators of positive affect contained in Lawton et al.’s (1996) scale were absent in severe dementia. Thus, the challenge for clinicians who are interested in deciphering the emotional state of those in advanced stages of dementia is great. At best, I could conclude that Anne and Isa were perhaps content and displayed low positive affect as evidenced by Watson & Tellegen’s (1985) description of low positive affect being “drowsy, dull, sleepy and sluggish” behaviour. There is little clinical utility to identifying a sleepy resident as having low positive affect and the validity of attributing this state is difficult to discern. Therefore, a more appropriate description of these two residents is necessary. The two case studies on advanced dementia best reflect the concepts of “connecting” from the perspective of the caregiver and “responding” from the perspective of the person with dementia.

The indicators of pleasure in the early to middle stages of AD have been established. Determining the sources of pleasure is largely supported by the retained communication abilities of people with AD. The dilemma is to discern what goes on in the advanced stages which were represented by Anne and Isa in this study. I struggled at length to try to identify a concept that captured the paucity of responses from these two participants while at the same time reflecting the interpretations applied by their family members and PSWs. Among the concepts I investigated were engagement, connecting and responding and I will describe the limitations attendant on each of them.
The concept of engagement has been described in the research literature focused on pleasant events for people with dementia. Engagement is defined as “any motor or verbal behavior exhibited in response to the activity in which the client was taking part” (Judge, Camp & Orsulic-Jeras, 2000, p.43). Passive engagement is defined as “listening and/or looking behavior exhibited in response to the activity the client was participating in” (Judge, Camp, & Orsulic-Jeras, p. 43). Non-engagement is defined as “staring off into space or another direction away from the activity, sleeping” (Judge, Camp, & Orsulic-Jeras, p. 43). Definitions of passive engagement and even non-engagement do not adequately describe the interactions demonstrated in the video recordings. The concept of passive engagement with advanced dementia does not work because the meaning from the perspective of the resident has to be imputed by caregivers and the mutuality from the perspective of the resident cannot be established. As well, the concept of engagement requires that the responsiveness of the people engaged can be linked to the actions of the initiator. This did not happen consistently even when there was some type of behavioural change on the part of those with advanced dementia and importantly, observable signs of pleasure were not present in these two residents with advanced dementia.

Family members and PSWs felt that they were able to connect while interacting with Anne and Isa and they identified responses to this connecting that satisfied their need to elicit a response of some sort from the resident. They often “just knew” that the resident was enjoying the interaction even though the resident did not show any recognizable signs of enjoyment or pleasure but did show some type of response. For example, any participation in an interaction, including grasping the caregiver’s hand was interpreted as meaningful. Dawson, Wells and Kline (1993) have noted that primitive
neurological reflexes including paratonia (muscle resistance to passive stretching of a limb), the suck and grasping reflexes have all been identified in people with AD. Interestingly, Isa’s grasping may have been a neurological reflex to her palm being touched, but her readily accepting spoonfuls of food is not demonstrative of the sucking reflex (Dawson et al.). Both families and PSWs predetermined that the resident liked certain things and went into the interaction prepared to demonstrate the already established enjoyable routine. These determinations were made by several processes including trial-and-error and drawing upon biographical meanings. However, the concept, to connect means “to have or establish a rapport” where rapport is defined as a “relation marked by harmony, conformity, accord or affinity” (Merriam Webster’s dictionary online). Great effort is exerted on the part of the family members and PSWs to connect with the resident and to see any response on the part of the person with severe dementia, when it follows an intervention meant to be pleasurable, as an indicator of pleasure. Connecting when used by caregivers, however, only refers to their sense of having a rapport and any response is viewed as evidence that they have connected. It is not possible to know if this is a mutual process, nor is it possible to know if the person with advanced dementia is experiencing pleasure during these interactions. A connection may be experienced by a caregiver when she or he and the resident are sitting together listening to music or during mealtime where the resident is participating by eating. When Anne was sitting in front of the television with a Broadway musical playing, it was Emily’s interpretation that Anne was listening and enjoying the musical. However, there were no observable signs of Anne’s participation in listening let alone enjoying it. While the musical played in the background Anne sat in her wheelchair with her head tilted
downward and her eyes closed. Her arms were resting by her side and her feet did not move during the music. It is important to note that the notion of observable signs of listening itself is problematic since it is a subjective state that may occur without any outward signs of enjoyment or participation in listening. In residents with advanced dementia, careproviders felt that they could connect with the person and believed that any response on the part of the person indicated a positive interaction if not pleasure. In this case, connecting refers to the caregivers’ belief that something occurs between residents with very advanced dementia and their caregivers based on the latter’s interpretation of the interaction.

There is variability in the level of participation displayed by different individuals with dementia: some display a subtle participation while others demonstrate a more obvious commitment to an interaction. For example, Anne was able to participate in her breakfast mealtime experience with her PSW through accepting spoonfuls of food and by moving her bib up to her face to wipe the corner of her mouth. Isa’s mealtime participation was different from Anne’s because her only response was to accept spoonfuls of food into her mouth and swallow. These two residents did not consistently respond to similar pleasurable stimuli in the same manner either. For example, the level of participation that Anne displayed during breakfast with Betty was much greater than with her daughter who fed her applesauce in the afternoon. Therefore, contextual, interpersonal and individual factors may mediate the person’s response and ability to engage with his or her caregiver.

Believing that they are able to connect with a resident with advanced dementia, is relevant for caregivers when people no longer smile, laugh, or otherwise express
indicators of pleasure. In people with severely advanced dementia any type of response to an overt pleasurable event is seen as connecting and as an indication of pleasure from the perspective of the careprovider. In other words, the degree to which or the intensity with which certain things are enjoyed cannot be known in the absence of a subjective account.

This analysis led me to reject the concepts of engagement and connecting as reasonable ways of understanding and describing what happens when a family member or careprovider reaches out to a person with advanced dementia with the intention of having that person enjoy the proffered action. Careproviders interpreted any response from the person with dementia to indicate the person’s participation in their moments together. Yet, what occurs on the part of the person with advanced dementia is not known although it became clear that it was important to the family and careproviders to provide opportunities for pleasurable interactions and to believe that the person enjoyed those interactions. It is possible to conclude that family members and PSWs believe it is important to work hard to elicit any response from residents with very advanced dementia. Whether or not these responses are indicative of pleasure is not known. The concept of personhood is relational and in struggling to understand how to interpret the responses demonstrated by residents with advanced dementia, it may be that the very responses from residents are reflective of personhood in the relationship with their caregivers and family.
Relating Results to Concepts:

Personhood, Relative well-being, Continuity of self and Selfhood

In contrast to authors who posited the loss of self with Alzheimer’s disease (e.g. Cohen & Eis dorfer, 1986; Herskovits, 1995), many others claim that personhood and selfhood remain intact in Alzheimer’s disease (Cowdell, 2006; Harrison, 1993; Kitwood, 1997; Kitwood & Bredin, 1992; Kontos, 2005; Lawton, 1997; Phinney, 2006). The concept of personhood has served gerontological nursing as a guiding principle that supports dignified and respectful care of persons with dementia. It has been argued that the concept of personhood ought to be expanded to include the concept of citizenship in order to broadly inform the next 10 years of dementia research and practice (Bartlett & O’Connor, 2007).

This research project was guided by the sensitizing concept of personhood. As noted in the concepts section of the report, Kitwood (1997) described seven psychosocial needs: comfort, the soothing of pain and sorrow and calming of anxiety; attachment, through creating bonds of belonging and safety; inclusion, having a place and role; occupation, knowing the person’s life history, tastes and preferences; identity, which refers to knowing details about a person’s life history so that even if the person cannot hang on to narrative identity others can; empathy for person “see them as Thou” (Buber as cited in Kitwood, 1997); and love. These psychosocial needs of individuals with dementia are key components to preserving personhood through positive interactions.

In this study family members and PSWs preserved the identity of the person, i.e. personhood with AD, through retelling their story. The video recorded interactions showed varying degrees of empathic interactions exhibited by the facial expressions of
the PSWs and family members while interacting with the resident. One of the key features of the video recorded interactions which aimed to demonstrate pleasurable moments between the resident and caregiver was the underlying relationship. Even in the case of a sexually aggressive resident the, PSW did not engage in an objectifying relationship but instead related to the resident as a person worthy of respect and dignified care thereby respecting the resident’s identity.

The interactions initiated by family members and PSWs provided the opportunity for their relatives to demonstrate relative well-being. Kitwood and Bredin (1992) described indicators of relative well-being in persons with dementia including: the assertion of desire or will; the ability to express a range of emotions (positive and negative); initiation of social contact; affectional warmth; humour; showing evident pleasure; helpfulness and relaxation. The “assertion of desire or will” refers to the resident’s ability to express acceptance or rejection of certain care procedures (Kitwood & Bredin). Emma clearly asserted her desire not to sit and have her make-up applied by PSW Jane, repeatedly asking to “lie down”. Mary expressed her desire not to go back to the floor (her room) after sitting downstairs with her daughter, Patsy. Mary retained the highest level of verbal communication skills and was able to verbally express her desire by asking if she had to return to the care unit. Marjie did not express a specific desire not to engage in activities and instead was eager to follow both her sister, Liz and PSW Teresa in whatever interaction they chose to initiate. She did not show the same degree of disagreement as either Emma or Mary did. Sylvia expressed her dislike for orange juice during mealtime by taking a sip and making a face that showed distaste for the juice. Her daughter explored this by asking her if it was sour tasting to which Sylvia did not respond,
but did not drink anymore of the juice during lunch. Sammy, who maintained some verbal ability, expressed a strong desire to go fishing and to go dancing. Anne and Isa, with very advanced dementia, are the two residents who did not overtly demonstrate the “assertion of desire or will” in ways that were apparent to me or to their PSW or family member.

The ability to experience a range of emotions (both positive and negative) (Kitwood & Bredin, 1992) and the initiation of social contact were not evident in Anne and Isa. Affectional warmth was expressed by Mary towards her daughter and her PSW through touch (holding hands or linking arms to walk together). Emma also expressed affectional warmth through touch with her daughter. Sylvia, although euphoric, did express affection towards her daughter by kissing her on both cheeks upon seeing her. In addition she kissed the PSW on her hand. Anne, Isa, Marjie, and Sammy did not show affectional warmth towards their family member or PSW. Instead the affectional warmth was conveyed to them by their family member and occasionally by their PSW. Marjie and Mary both showed a sense of humour by laughing appropriately during their interaction. Emma made an effort to demonstrate helpfulness by trying to tidy the tables after mealtime and trying to feed another resident. It is difficult to know whether Anne and Isa were showing signs of relaxation, but certainly their relaxed posture and lack of expression of negative affect may suggest that during certain periods of rest they may be experiencing relative well-being through relaxation.

In advanced dementia indicators of selfhood are accessible because they encompass the life history of the person with dementia. Sabat (2001) defined three aspects of the self in dementia: self one, the self of personal identity; self two, the self of
mental and physical attributes and; self three: personae (Sabat, 2001; 2002). For example, family members drew upon self three or personae in order to suggest what the person may still enjoy or derive pleasure from. Personal identity is thought to be expressed through the use of personal pronouns such as “I”, “me” or pointing to oneself (Sabat). In residents with early to moderate dementia this may be possible; however, in severe dementia once language wanes, verbal expressions are not possible (Tappen, Williams, Fishman & Touhy, 1999). Building on the concept of selfhood, Kontos (2005) proposed the concept of “embodied selfhood” through in-depth observational qualitative research methods.

Embodied selfhood is defined as:

The way that persons with dementia unthinkingly carry and project their bodies with coherence; the often subtle attentiveness to their appearance, cleanliness, and social etiquette; bodily expressions of class distinction; and the spontaneity to their actions (Kontos, p. 565).

Non-verbal interactions and expressive gestures in people with impaired verbal communication were also thought to be meaningful in Kontos’ interpretation of embodied selfhood. Attentiveness to appearance was important to Emma and Sylvia whereas, it was not important to Mary and Marjie as evidenced by their different approaches to dressing, hairstyle and make-up. For other residents, like Anne and Isa, PSWs regarded appearance as important by paying attention to their clothing and jewellery and hair and make-up for the day. The importance that Kontos places on gestures in signifying unique manifestations of selfhood is one aspect of pleasure. For example, Emma smiled when showing her polished nails to the camera while I was video recording her and Jane, the
PSW, applying nail polish to her fingernails. The case studies all showed evidence of continuity of selfhood. Whether selfhood is defined by past roles, personal identity and personae or as an embodiment, family members described the person as maintaining aspects of their previous personality. While there were new sources of pleasure identified, there was continuity in sources of pleasure with maintained abilities. The ability to initiate pleasurable interactions was not present in residents with advanced dementia. They required initiation from a caregiver and would then follow through with varying levels of response.

This study further defines the experience of family members as a struggle to define what is pleasurable in the resident. The caregiver’s perspective was not the focus of Kitwood and Bredin’s (1992) work, instead, their focus was on the person with dementia and his or her well-being. The efforts at connecting with the residents with very advanced dementia can be interpreted as supporting their personhood and selfhood. Although all of the caregiver interactions in this research were person-centred, there is also the possibility that caregivers may undermine personhood through negative interactions and inappropriate communication (Savundranayagam, Ryan, Anas, & Orange, 2007).

Because of the importance they placed on the relationship with the residents, family members bound by love and filial piety and PSWs bound by friendship and professionalism, served to respect the personhood of the residents with whom they interacted.
CHAPTER 8: CONCLUSIONS

This study examined four research questions about how family members create pleasurable experiences in their relative; how they draw on biographical meaning in creating these experiences; what indicators they use to determine whether or not their relative is experiencing positive emotions; and what happens when a PSW is shown a video recording of a pleasure-inducing activity and is asked to replicate that interaction with the resident. It is possible to conclude from the results of this study that (a) sources of pleasure were lost, retained and acquired; (b) PSWs and family members described and demonstrated knowing what to do to elicit pleasure; (c) PSWs and family members also had an understanding of indicators of pleasure; (d) there was a continuity to the personality of residents when their family members drew upon their biographical meanings and life history; (e) PSWs did not consistently replicate pleasurable interactions demonstrated by family members and were able to show something that was unique to their relationship with the resident; and (f) indicators of pleasure are not found in those with advanced dementia although family members and PSWs continue to try to elicit a response from them but sweet tasting food, some types of touch and music all elicited some responses from the residents some of the time. These results were discussed in three overall areas: (1) family members struggle to know what to do; (2) PSWs’ knowledge about pleasure in residents; and (3) the overall concept of pleasure in advanced dementia.

Given the available theoretical paradigms, it is also possible to conclude, based on the results of this study, that an abilities focused care approach to caregiving is preferable to a retrogenic model since the former allows for the preservation of dignified care and minimizes the over reliance on infant and child analogies for care. Family members based
their opinions about what to do during a visit on the person’s previous personality and previous likes, and used trial-and-error along with this knowledge to make decisions.

PSWs did not describe the struggle to determine what to do as much as families did; instead, their interviews demonstrated a confidence in knowing the person with AD. Furthermore, PSWs took pride in demonstrating their knowledge about what brings about joy in the residents. This may be explained by their level of experience working in long-term care and their expertise in caregiving and long standing relationship with the residents. Because the residents with advanced dementia cannot communicate their preferences, they were more challenging for and created some uncertainty in PSWs.

Positive affect has been defined as pleasure, joy and interest. Measurement tools such as the AARS (Lawton, Van Haitsma, & Klapper, 1996) are useful in the early to mid stages of AD; however, when the person no longer expresses affect in terms of the indicators in this measurement tool, it is unclear what emotion the person is feeling internally because the external indicators have ceased. For the two residents with advanced dementia, both PSWs and family members could always describe how they elicited a response when interacting with the resident. Some of the responses they elicited from the residents where, for example, through tighter grasping of their hands by the resident or of eating a meal by readily accepting spoonfuls of food while being fed.

Touch, sweet taste and listening to music were the three sensory experiences that were thought to bring about positive affect in residents with advanced dementia from the family and PSW perspectives. When the resident’s body language, facial expression and verbalizations cease to indicate overt and established indicators of pleasure such as smiling, laughing, and positive phrases, family members and PSWs relied on their own
sense of whether they are able to *connect* with the resident they are interacting with. Everyone has the right to the highest quality of life possible and that right does not diminish with a decline in cognitive abilities. Therefore, when the smiling stops it is imperative that caregivers continue to pursue ways of establishing a connection with the person living with advanced dementia.
CHAPTER 9: IMPLICATIONS FOR CLINICAL PRACTICE, FUTURE RESEARCH AND EDUCATION

Implications for Clinical Practice

This study provides a beginning understanding of how PSWs are sources of information about residents with whom they have worked for a substantial period of time in a particular setting. The admission process in long-term care incorporates documentation about the person’s daily routines and preferences from the perspective of the individual if able to communicate and if not from their family member(s) but as time passes and PSWs become familiar with residents they too may be sources of knowledge about preferences and about what creates pleasure in the resident with AD. There is an opportunity for long-term care facilities to capitalize on this knowledge in a formal way through documentation in the medical record so that a continuous plan of care may be followed by all staff that interacts with a resident. PSWs who have had a long standing working relationship with a resident are often knowledgeable about the particularities of how to maximize the interactions to bring about positive affect in residents with advanced AD.

The importance of creating positive affect has not been strongly argued for in long-term care. For example, research on sensory experiences (e.g. art, music, taste, touch, and aromatherapy) has focused on the outcomes of reducing aggression using nonpharmacologic interventions (Buettner, 1998; Camp, Cohen-Mansfield, Capezuti, 2002; Holmes et al., 2002; Lou, 2001). Aggression (also referred to as agitation) is the only emotion that has been described well and researched in people with dementia. For example, Cohen-Mansfield (1996), views verbal and physical agitation as a potential
expression of unmet needs and is largely focused on managing disruptive behaviours. The issue of pain in dementia has over nine assessment scales ranging from self-report, informant rating and observational assessments (Cohen-Mansfield, 2008). However, there are only two observational scales to measure positive affect in dementia, the Apparent Affect Rating Scale (Lawton et al., 1996) and the Apparent Emotion Rating Inventory (AERI) (Snyder et al., 1998). The AERI has not been psychometrically tested in studies beyond Snyder et al.’s initial conceptualization of it. Certainly the under detection of pain in residents with dementia is a serious quality of life issue but I would argue for the importance of detecting the presence of pleasure in the daily lives of residents with dementia in order to insure opportunities are created. Opportunities for using touch, sweets and music very deliberately throughout the day to bring about pleasure in residents and to connect with those in the advanced stages of dementia have the potential to enhance the quality of that moment for the residents.

Implications for Future Research

Future research should focus on at least four objectives. First, to understand fully the nature of responses seen in residents with advanced dementia, such as discerning whether grasping the hands of a caregiver represents a retained primitive reflex or a positive response to having another person to visit and interact with. Perhaps physiological indicators could be pursued such as heart rate or respiratory rate as potential indicators of the person’s mood state. Second, to further our understanding of positive affect in people with advanced dementia through employing quantitative research methods to develop and test a tool to measure the frequency, intensity and duration of positive affect in advanced dementia. For example, Porzsolt and colleagues
(2004) developed a proxy rating measurement tool for well-being in advanced dementia and similar methods may be used to develop a tool to measure affect in advanced dementia. This would help to overcome the difficulty of measuring subjective states on the basis of a person’s cognitive impairment. The third objective is to use an interdisciplinary perspective to develop and evaluate pleasure-inducing interventions for residents in long-term care settings. Collaboration with PSWs and family members is critical because they have been shown in this study to have knowledge about residents’ preferences. Fourth, to explore using qualitative interviews and observation, how positive affect in residents with dementia influences the caregivers and the care context in long-term care environments. Given that strategies to bring about pleasure can occur during routine ADLs with caregivers, it may be helpful to understand more about how caregivers make decisions about how to interact with residents and to further understand the value they place on positive affect as an outcome measure of their interactions with residents.

In order to explore the concept of pleasure in advanced dementia further, future research might focus on positive affect in varying cultures since expressions of emotion are culturally based (Ekman & Friessen, 1978). Future research could also explore the concept of connection in advanced dementia. This study found that in the two residents living with advanced dementia, positive affect was not observable but the concept of establishing a meaningful connection from the perspective of the caregiver was important and thought to be pleasurable for the resident. Future case study research might explore this population further and this concept of connection. Perhaps a different methodology could be used such as a focused ethnography that would allow for a broader perspective on pleasure encompassing the entire long-term care environment.
Implications for Education

Gerontological nursing content is lacking in undergraduate and graduate nursing programs. In fact, Rosenfeld, Bottrell, Fulmer and Mezey (1999) estimated that fewer than 25% of baccalaureate nursing programs in the United States of America required courses in gerontological nursing. There are no data available on the gerontological content that is included in the PSW curriculum and the occupation itself is unregulated. Despite these challenges there is an opportunity for nursing and PSW programs to integrate content on communication with people with dementia. One key aspect of communication in this population is to understand expressions of positive and negative affect. Research has been done on the impact of training staff caregivers to be sensitive to nonverbal emotional expressions in people with dementia (Magai, Cohen & Gomberg, 2002). While training staff is one aspect so is eliciting their knowledge of the residents. This study concluded that PSWs who have worked with residents consistently and for over a period of three months or more are knowledgeable about positive affect and can connect with residents with advanced dementia. Therefore, facility based educational sessions might focus on capitalizing on their knowledge through an interactive teaching module. For example, instead of employing the traditional lecture format where PSWs are taught what to do and strategies for communication, they could also be asked to problem solve and generate ideas about what they have seen work with residents and contribute to the group’s learning in that way. Through their prolonged experiences working with residents in long-term care PSWs may be more knowledgeable about pleasure than RNs or RPNs. Intraprofessional educational efforts focused on pleasure and the importance of learning how to integrate pleasurable interactions into the daily
care practices of PSWs, RNs and RPNs, is needed. For example, if the resident is newly admitted to the long-term care home, the social worker may be a key member in informing the PSWs about what the person’s past preferences were based on their in-home assessments or a physiotherapist who has worked out a mobility schedule and techniques with a resident for whom walking is pleasurable, could teach the PSWs how to integrate short walks into their routine. Similarly, PSWs who have worked with residents on an ongoing basis and may have collaborated with family members can become leaders in informing the rest of the care team about sources and indicators of pleasure in the resident. Since these practices may not occur consistently across facilities, educational agendas need to focus on integrating the assessment, treatment and evaluation of affect and teach about pleasure in people with dementia.

The video-recording method was a useful educational tool for the PSWs in this study. Therefore, using video recorded segments to demonstrate pleasurable and enjoyable interactions to learners may also be employed in curriculum programs. If it is challenging to get ethical approval to use actual residents in these teaching tools, it may be feasible to employ actors to construct a situation that would demonstrate the necessary principles including facial expression, gestures, and verbalizations. Some research has used video taped interactions successfully with training nurses in evaluating their communication style and overall bedside manner with clients (Caris-Verhallen et al., 2000) and with training PSWs on how to use the AARS (Lawton et al., 1993). Napholz and McCanse (1994) found that interactive video instruction increased the efficiency in cognitive learning with undergraduate nursing students. In the interest of advancing the development of gerontological content, nursing undergraduate and graduate curricula
should integrate assessment, intervention and evaluation strategies related to pleasure and positive affect in people with dementia. PSW training programs should also require students who plan to work in long-term care with clients with dementia to learn how to bring about pleasant moments and to recognize indicators that the person is content, interested or enjoying him/herself during caregiving interactions or during social interactions throughout the day.

RNs and RPNs working with residents with dementia should also be taught about the concepts of personhood and selfhood to see how creating opportunities for pleasure should be incorporated into their care routines. According to Parahoo, Whall, Colling and Nusbaum (2006) expert nurses use many different sources of knowledge in decision making about persons with AD. They found that expert nurses used experiential knowledge, ethical knowledge, theoretical knowledge, intuition and reflective practice (Parahoo et al., p. 568). In order to enact such expertise nurses must first know the resident. RNs and RPNs working in long-term care, complex continuing care, and acute care hospital units may find themselves caring for persons with AD. In order to fully understand the resident’s lived experiences RNs and RPNs need to be taught to view creating pleasure as important as creating cleanliness, providing feeding support and managing basic ADLs. A whole person approach is required to maximize quality of life in long-term care for residents living with dementia. The RNs, RPNs and PSWs can all work as a team to assess, monitor and evaluate pleasure as it is an emotion that requires the initiation of pleasurable interactions by caregivers as dementia advances in residents living in long-term care facilities.
Despite all of the losses, pleasurable emotions are still possible for those with moderately severe dementia. This collective case study found that sources of pleasure are retained until the very severe stage where any response is seen as meaningful. Thus, pleasurable interactions should be incorporated into standard nursing care plans.

Everyone has the right to a good quality of life. Quality of the moment matters especially for people living with advanced DAT. Taking the time to bring about a positive emotion through considering whether a gentle touch is needed, a sweet should be offered, a radio should be tuned to a once-loved station, or some other potential pleasurable interaction be employed will contribute to exceptional care of Canadians living with Alzheimer’s disease.
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Appendix A

Literature Review Tables
Table 1: Intervention Studies: Stimulation-oriented approaches: Activity therapy

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<tr>
<th>Authors</th>
<th>Setting and sample</th>
<th>Design</th>
<th>Purpose of study</th>
<th>Effect Variables</th>
<th>Intervention</th>
<th>Measuring instruments</th>
<th>Results</th>
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<tr>
<td>Althus, Engelman &amp; Mathews (2002)</td>
<td>locked dementia unit; CNA = 2; N = 6 residents; mean age = 79 years (range 61-89 years); mean MMSE = 6.3 (range 1-13)</td>
<td>Control series design</td>
<td>Purpose: to see whether a recording and feedback procedure for staff would be enough to increase resident engagement in daily activities</td>
<td>1. Engagement</td>
<td>Control series design Baseline engagement observations Observations under treatment conditions where CNAs completed a daily activity record of the amount and quality of resident engagement. The activity director would give daily positive feedback to the CNAs on the activity records.</td>
<td>• Activities, • Activity prompts, • Praise and • Other contacts with residents were observed and recorded</td>
<td>• Mean inter-observer agreement = 91% • Baseline engagement observations mean of 11% • Treatment observations increased to mean of 44% • Actual activities were not reported</td>
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<td>Baker et al., (2003)</td>
<td>Day hospital in the UK and psycho-geriatric wards in the Netherlands and Sweden; N = 136 patients; mean age 82 years; MMSE range from 0-17</td>
<td>RCT</td>
<td>To compare the effects of 8 standardized multisensory stimulation (MSS) programmes with a control condition of activity sessions.</td>
<td>1. behaviour 2. mood 3. cognition</td>
<td>Eight, 30-minute sessions on MSS (n = 65) or Activity (n = 71). Programs implemented 2 times/week for 30 minutes for 4 weeks for both groups. MSS – light and sound effects, materials for touching and smelling. Activity sessions – playing cards, doing quizzes, looking at photographs.</td>
<td>• Interact rating form • BMD scale • BRS • CAS • MMSE • REHAB</td>
<td>Both one-to-one MSS and Activity: • Improved behaviour and mood • Increased verbal communication and memory recall • Decreased non-social behaviour at home Therefore, MSS was not better than activities in changing mood, cognition of behaviours in dementia.</td>
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Notes. RCT = randomized controlled trial, Ss = subjects, RA = research assistant; MMSE = Mini Mental State; SCU = special care unit; AD = Alzheimer’s disease; CNA = certified nursing assistant; CMAI = Cohen-Mansfield Agitation Inventory; MOSES = Multidimensional Observation Scale for Elderly Subjects; CAPE = Clifton Assessment Procedures for the Elderly; CAS = Cognitive Assessment Scale of the CAPE; BMD = Behaviour and Mood Disturbance Scale; BRS = Behaviour Rating Scale of the CAPE; ABS = Adaptive Behaviour Scale
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<tr>
<td>Brooker &amp; Duce (2000)</td>
<td>day hospital; n = 25 with diagnosis of mild to moderate dementia; age range = 76.1-90.3 years; staff patient ration 1:3 or 1:4</td>
<td>within-subjects repeated measures;</td>
<td>To compare levels of wellbeing shown by people with mild to moderate dementia during three types of activity.</td>
<td>1. Well-being</td>
<td>Intervention: 3 types of activity: reminiscence therapy (RT), group activities (GA) and unstructured time (UT)</td>
<td>• Dementia Care Mapping</td>
<td>• Individuals experienced more wellbeing during RT than GA; • wellbeing in both RT and GA was significantly higher than UT.</td>
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<tr>
<td>Buettner (1999)</td>
<td>dementia SCUs; n = 55 residents mean age = 87.4 years; mean MMSE = 6.7; n = 43 staff members</td>
<td>Cross-over design</td>
<td>To investigate the effects of 30 handmade recreational items on the behaviour of nursing home residents with dementia.</td>
<td>Satisfaction</td>
<td>30 simple pleasure handmade items such as: an activity apron, stuffed butterfly, cart for wandering; fishing box; flower arranging; electronic busy box; hang the laundry; home decorator books; latch box-doors; look inside purse; message magnets; muffs; picture dominoes; polar fleece hot water bottle; rings on hooks game; sewing cards; squeezies; table ball game; tablecloth with activities; tetherball game; vests/sensory; and wave machines</td>
<td>• CMAI • MMSE • Penn State Nursing Home Survey • Scanning the Environment Tool • Time Engaged with Item Tool (developed by research team)</td>
<td>• 23 of the 30 items were found to be therapeutically valuable for nursing home use. • There was a slight to significant decline in agitation in nursing home residents. • Family visits significantly improved during the simple pleasures intervention. • The impact on staff was not reflected in the data collected although direct observation showed some evidence of use by staff during routine care (i.e. medication administration, bathing)</td>
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<td>Crispi &amp; Heitner</td>
<td>nursing home; n = 29 family member and resident dyads; mean age of resident = 86 years (range 67-99); diagnosis of dementia</td>
<td>intervention pilot study</td>
<td>The aim of the study is three fold: to offer families a series of activity kits that they could use in their visits; to have them evaluate the kits and to replicate the program independently demonstrating its usefulness in other settings.</td>
<td>N/A</td>
<td>Families used the activity kits during their visits with relatives for 12 weeks while concurrently evaluating the kits. The kits that remained (after families eliminated less useful ones) were implemented in a different facility.</td>
<td>Evaluation form for activity kits (developed by research team)</td>
<td>Puzzles and reminiscence kits contributed more to the visits than any other kit and the least valuable kits were the sounds of the past kit and the games kits.</td>
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<td>Kolanowski, Buettner, Costa &amp; Litaker, (2001)</td>
<td>nursing home; n =10</td>
<td>Crossover experimental design</td>
<td>“To test the utility of theory-based activity selection for treating behaviours commonly exhibited by people with dementia” (p. 225)</td>
<td>1. Affect 2. Agitation</td>
<td>Treatment group: activities matched to style of interest using Simple Pleasures © activities; control group activities not described; washout period = 2 days</td>
<td>Engagement Instruments:  • Philadelphia Geriatric Center Affect Rating Scale  • Dementia Mood Picture Test  • CMAI  • MMSE  • Psycho-geriatric Dependency Rating Scale  • NEO Five Factor Inventory</td>
<td>Treatment activities resulted in more engagement and greater displays of positive affect than during control activities.</td>
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<td>Kovach &amp; Henschel (1996)</td>
<td>Special Care units; N = 23; mean MMSE = 15.93 (range 4-24); mean age = 83 years (range 70-93) “moderately functioning individuals in mid-stage dementia” (p. 37)</td>
<td>Direct observation</td>
<td>• To describe the therapeutic activity experience through repeated observations during music therapy, art therapy, exercise, a cognitive activity, and functional household activities (cooking, dishwashing and folding towels)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>• Less structured activities were associated with self-revelation and spontaneity; • an enthusiastic and structured leader was associated with keeping people actively involved, positive affect behaviours and verbalization.</td>
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<td>Long Foley, Sudha, Sloane &amp; Gold (2003)</td>
<td>36 Special Care units; n = 70 residents; 51 nursing staff; 10 activities or social work staff; 27 unit coordinators</td>
<td>Qualitative interviews</td>
<td>• To examine the relationship between demographic and behavioural characteristics of residents, management techniques of staff and family participation in the management of residents with severe behavioural problems.</td>
<td>N/A</td>
<td>Sensory activity (ball toss, playing cards, walks, telephoning, sweets, stuffed toy or doll) intervention to manage behavioural problems</td>
<td>N/A</td>
<td>• Family involvement was crucial to resident success • Use of many non-pharmacological techniques was associated with better management than with other techniques • Sensory activities (e.g. ball toss, play cards) was used 21.4% of residents • 10% were taken for walks; 5% phoned a friend or relative • Less than 5% of residents were given sweets, used a stuffed toy or doll and brought children to the unit.</td>
</tr>
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</table>
### Moffat et al., (1993)

|   | Day hospital females with dementia (n = 6), males on a continuing care ward in England with senile dementia and moderate to severe cognitive impairment (n = 6) | Multiple baseline design across subjects | To examine the effects of Snoezelen intervention on family caregivers and patients. | 1. behaviour 2. mood | Baseline for 3, 4 or 5 weeks followed by 4 weeks of 3 hours per week of Snoezelen per week. | N/A | Patient:  
- increased happiness and interest  
- decreased sadness, agitation and anxiety  
- improved mood during follow-up and decreased stresses |

### Orsulic-Jeras, Judge, & Camp (2000)

|   | step-down advanced dementia unit; n = 16; MMSE mean = 6.1 (range 0-19); aged 79-94 years, mean | control group and intervention group | To examine the effects of Montessori-based activities programming on specific types of engagement and affect in residents with dementia living in long-term care | 1. Affect 2. Engagement | Control group = regularly scheduled programming by activities therapist. Montessori-based programming occurred concurrently with same participants (serving as their own) | Engagement measure Affect Rating Scale | Patient:  
- Affect: Pleasure – significantly higher during Montessori programming. Anxiety/fear – levels of anxiety were higher in regular programming. Anger and sadness – rarely observed, but when they were, they occurred in |
| Orsulic-Jeras, Schneider, & Camp (2000) | day care; n=25; MMSE mean = 11 (range 0-23); mean Age = 88 years (range 75-103) | intervention study | To compare the effects of Montessori-based activities to regular activities programming. | 1. Agitation 2. Engagement 3. Affect | Intervention group: twice weekly Individual Montessori programming; group Montessori-based activities | regular programming not during Montessori programming.  
- Engagement:  
  - Constructive engagement (CE): more CE was observed during Montessori programming than during regular programming.  
  - Passive engagement (PE): residents showed less PE during Montessori programming.  
- Nonengagement (NE) and self-engagement (SE): not often observed, when they were seen they occurred exclusively during regular programming. | controls). Individual activities and small group activities (memory bingo and group sorting) were offered from simple to complex. | MOSES, MMSE, Myers Menorah Park/ Montessori Assessment system  
- CMAI  
- Cornell Scale for Depression  
- Constructive and Passive engagement | “Montessori programming resulted in more constructive engagement and pleasure and less passive engagement and negative affect than other programming” (p.78)  
- Significant programming effects for Constructive engagement, passive engagement, and pleasure. |
<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Participants</th>
<th>Methodology</th>
<th>Outcomes</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Palo- Bengtsson &amp; Ekman (2002)</td>
<td>Nursing home residents N = 5; Day care program participants N= 1</td>
<td>Qualitative study using descriptive phenomenological method for data analysis</td>
<td>To understand the feasibility, popularity, and meaning of social dancing and walks in people with dementia.</td>
<td>Observational data collected using video-taping during one dance session and one walk session for each participant.</td>
<td>• Four themes describing individual’s response: &quot;1) the engaged body; 2) the caregivers’ understanding, encouragement and response to patients during the activity; 3) mutual tenderness and communion; and 4) environmental conditions.” (p. 151)</td>
</tr>
<tr>
<td>Rentz, (2002)</td>
<td>Nursing home adult day program; N=41 participants</td>
<td>Pilot project evaluation</td>
<td>To examine if participation in art activities contributes to the individual’s sense of well-being.</td>
<td>“Memories in the Making™” art program for people in the early stage of AD</td>
<td>• Psychologic al well-being instrument designed for this study based on Lawton’s conceptualization of psychological well-being</td>
</tr>
<tr>
<td>Schneider &amp; Camp (2002)</td>
<td>Nursing home; n = 12 resident and visitor dyads; ½ of the residents MMSE&lt;10 = advanced dementia</td>
<td>Quasi-experimental pre-test – post-test;</td>
<td>To examine the effects of Montessori-based activities during nursing home visits.</td>
<td>1. resident engagement 2. caregiver burden 3. life satisfaction 4. mastery</td>
<td>• Resident’s use of Montessori-based activities was associated with significant increases in resident engagement with visitors and decrease in passive engagement. • Visitors’ self-reported burden decreased from pre-test (22.4) to post test (19.9).</td>
</tr>
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</table>
for 5 minutes early and 5 minutes later in the visit; during that same 3 weeks the researcher met with the residents and introduced Montessori-based activities; visitors watched researchers working with residents during the training phase (2 to 5 visits); during the final phase researchers observed the residents’ engagement and affect during 4 visits while family members implemented Montessori-based activities. Examples of Montessori-based activities include category sorts; category matching; motor (fruit/vegetable shopping; golf ball scoop) and sensory (thermic tablets, slides of participants artwork) activities (p. 76)

<table>
<thead>
<tr>
<th>Sherratt, Thornton &amp;</th>
<th>N = 24; 16 from</th>
<th>Observational study using an</th>
<th>To examine “the impact of social 1. well-being</th>
<th>Four counter-balancing conditions:</th>
<th>• Dementia Care Mapping</th>
<th>• “live music was significantly more effective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Authors</td>
<td>Location</td>
<td>Sample Size</td>
<td>Design</td>
<td>Objective</td>
<td>Intervention</td>
<td>Results</td>
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<tr>
<td>Hatton (2004)</td>
<td>continuing care ward and 7 from day hospital with moderate-to-severe dementia;</td>
<td>experimental, within-participants, repeated measures design.</td>
<td>interaction in music listening on behavioural responses of people with moderate to severe dementia” (p. 233)</td>
<td>2. engagement 3. challenging behaviours</td>
<td>No music, taped commercial music, taped music played by a musician and live music (p. 235)</td>
<td>in increasing levels of engagement and well-being regardless of level of cognitive impairment” (p. 233) • Implication for using live music in dementia care settings aimed at reducing challenging behaviours</td>
</tr>
<tr>
<td>Smallwood et al. (2001)</td>
<td>nursing home; n = 21</td>
<td>RCT</td>
<td>To determine the relaxing effects of aromatherapy massage on agitation and behavioural disturbances in dementia.</td>
<td>1. excessive motor behaviour</td>
<td>Three groups: aromatherapy and massage (AM); conversation and aromatherapy (CA); and massage only (M)</td>
<td>• behaviour was video-recorded; • video records were sampled once every 30 seconds rated by 2 individuals using Bowie and Mountain behaviour categories (neutral behaviour, motor, self-care, receiving care, external behaviour and inappropriate) • AM showed the greatest reduction in excessive motor behaviour of the other groups between 3-4pm. • Inter-rater agreement across the random sample of 20% of the records was 86%.</td>
</tr>
<tr>
<td>Snyder et al. (2001)</td>
<td>nursing home; n = 30</td>
<td>Quasi-experimental repeated measures design</td>
<td>To measure the effects of a glider swing intervention on emotions, relaxation and aggressive behaviors in</td>
<td>1. Emotions 2. Relaxation 3. Aggressive behaviours</td>
<td>20 day period = 5 days baseline observation; 10 days intervention phase; 5 days post treatment observation. 20 minutes of swinging,</td>
<td>• Emotions and relaxation significantly improved peaking at 10 minutes of swinging. • No differences were found in aggressive behaviors.</td>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Design</td>
<td>Objectives</td>
<td>Measures</td>
<td>Findings</td>
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<tr>
<td>Spaull, Leach, &amp; Frampton (1998)</td>
<td>England, psychiatric continuing care unit; all males with severe cognitive impairment (n = 8); restless behaviour (n = 3); communication problems (n = 2)</td>
<td>Multiple case design</td>
<td>To determine the effects of Snoezelen intervention</td>
<td>1. interaction 2. behavioural disturbances 3. increased interaction, interest and active looking 4. decreased unadjusted and provocative behaviour 5. no difference in well-being</td>
<td>During Snoezelen intervention increased interaction, interest and active looking Decreased unadjusted and provocative behaviour 10-min after, no difference in well-being</td>
<td></td>
</tr>
<tr>
<td>Teri &amp; Logsdon (1991)</td>
<td>Not specified</td>
<td>Evaluation of a tool</td>
<td>To describe the Pleasant Events Schedule-AD (PES-AD)</td>
<td>An inventory of 53 activities designed to assist caregivers in identifying appropriate pleasant activities throughout the course of AD. Assesses frequency, usefulness, and caregivers' enjoyment of activities.</td>
<td>In moderately to severely demented community residing patients caregivers reported ease of use useful in determining pleasant activities Limitation: no</td>
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<tr>
<td>Study</td>
<td>Setting</td>
<td>Methodology</td>
<td>Objective</td>
<td>Interventions</td>
<td>Outcome</td>
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<tr>
<td>Witucki &amp; Twibell</td>
<td>Long-term care facility; N =15 with advanced AD; MMSE scores between 0-2; Mean age 81.13 years range 60-95 years; Mean length of stay 4.24 years range of 0.7-9.3 years.</td>
<td>Intervention study</td>
<td>To examine the effect of sensory stimulation activities on the psychological well-being of residents with advanced AD.</td>
<td>Positive and negative affect Three sensory stimulation activities: music, touch and smell. Music (playing recorded selections of known preferred music for 5 minutes) Touch (holding hands and massaging with lotion for 5 minutes) Smell (odors including orange, cinnamon, coffee, chocolate or flowers presented for 5 minutes)</td>
<td>Discomfort Scale for Dementias of the Alzheimer Type (DS-DAT) • Mean baseline scores indicated participants had a moderately high level of discomfort • Overall discomfort decreased significantly during music, touch and smell interventions. • Fidgeting body language decreased significantly during all three sensory stimulation activities.</td>
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</table>
### Table 2: Cognition Based Therapy

<table>
<thead>
<tr>
<th>Authors</th>
<th>Setting and sample</th>
<th>Design</th>
<th>Purpose of study</th>
<th>Intervention</th>
<th>Measuring instruments</th>
<th>Results</th>
</tr>
</thead>
</table>
| Spector, Orrell, Davies, & Woods (2001) | 3 residential homes associated with a day center 27 participants with dementia (10 in control group; 17 in experimental group); mean age 85.7 years (range 71-95 years); 10 family members; MMSE 11.5-15.5 | RCT Pilot study of cognitive therapy program for dementia | Development of an implementation program of cognition-based (reality orientation and related approaches) therapies for dementia. | 15 session programme in 4 phases: (1) the senses (sound, vision, smell, taste, touch), (2) remembering the past (reminiscence), (3) people and objects (family and familiar objects), (4) everyday practical issues (finding your way around) | • MMSE  
• Alzheimer’s Disease Assessment Scale  
• Holden Communication Scale  
• Clinical Dementia Rating  
• Cornell Scale for Depression in Dementia  
• Rating Anxiety in dementia  
• Behaviour Rating Scale  
• General Health Questionnaire  
• Relative’s Stress Scale | • 45-min twice weekly sessions are associated with reduced depression and anxiety following treatment |
| Tappen, Williams, Barry & DiSesa (2001) | nursing home; n = 55 | RCT | To compare the effects of conversation intervention with exercise on the verbal communication performance of people with Alzheimer’s disease living in a nursing home. | Conversation treatment was given 3 times weekly for 30 minutes for 16 weeks | • MMSE  
• Picture Description Test  
• Number of words and information units was also collected. | • All groups declined in total number of words used; conversation-only participants performance was better for number of nonredundant units of information produced (p = .0433) and conciseness (p =.0101) |
Table 3: Time use in long-term care

<table>
<thead>
<tr>
<th>Authors</th>
<th>Setting and sample</th>
<th>Design</th>
<th>Purpose of study</th>
<th>Method</th>
<th>Measuring instruments</th>
<th>Results</th>
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<tbody>
<tr>
<td>Armstrong-Esther, Browne, &amp; McAfee (1994)</td>
<td>Acute medical geriatric unit and psychiatric unit; n= 24 3 groups: lucid: n = 8, mean age 82 years (range 76-90 years); CAPE score ≥ 9 confused: n = 81, mean age = 79 years (range 71-86 years); CAPE score 5-7 severely confused: n= 8, mean age 83 years (range 76-90 years); CAPE score 0-4. Nurse subjects: N = 306</td>
<td>Non-participant direct observation Nurses: self-administered questionnaire</td>
<td>Question: “do nurses attach great importance to talking to patients, and do they really spend much time doing it?” (p. 265)</td>
<td>30-minute observation during morning (0900 to 1200 hours) and afternoon (1400-1700 hours)sessions on Tuesday, Wednesday and Thursday for a 2-week period</td>
<td>• Clifton Assessment Procedures for the Elderly (CAPE)(cognitive and behavioural functioning) • Kind of behaviour and with whom was recorded using ‘Ethnogram’ microcomputer</td>
<td>• Demented subjects: 45% of time in solitary activities; when engaged, more with others than staff • Confused: 71% of time with others; 15% of time in solitary activities and 14% of time interacting with staff • Lucid: 84% of time in contact with others; 9% of time in solitary activities and 7% of time engaging with staff • Nurses’ questionnaire (74% response rate) ranked talking to patients as most important, rewarding and enjoyable.</td>
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<td>Ice (2002)</td>
<td>Nursing home n = 27; mean age = 85 years (range 65 – 100 years); 78% women, 90% white; 78% widowed</td>
<td>Observational</td>
<td>To determine how residents actually spend their day.</td>
<td>Each participant was observed for approximately 13 h on 1 day (8 am to bedtime)</td>
<td>• Data sheet recording location, position, mood, activity, number of people in the vicinity and ambient noise in the area.</td>
<td>• Location: 43% of time spent in rooms, an average of 25.4% of time in dining room; 25.6% of time in “parking areas; 4.2% of time in activity areas. Position: sitting for 69% of day; reclined in bed for a third of the day.</td>
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</table>
Mood: neutral 91.7% of the time; negative affect 7.3% of the time; almost never showed positive affect.

- **Group size**: 37% by themselves; an average of 20.6% with 1-2 people; 12.5% of time in small groups of 3-5 people and 10% of time in medium-sized groups of 6-10 people and 18.9% of time in large groups of 10 or more people.

- **Activities**: 65% of day in passive activities (sleep, nothing, fidget, waiting, television, look/listen, read); 18% in personal care activities and 12% of time in social activity.

<table>
<thead>
<tr>
<th>Nolan, Grant &amp; Nolan (1995)</th>
<th>Continuing care hospital Respite, long-stay and short-stay</th>
<th>Case study – unit was the focus of observation</th>
<th>To examine the activity and interaction levels amongst three different populations of elderly people (long-stay, short-stay and respite)</th>
<th>Structured observations reported here (overall study used semi-structured interviews, profiles for each patient, structured observations, questionnaires and participant observation)</th>
<th>4-categories of observation: passive; instrumental; constructive; and other</th>
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- Respite and short-stay patients were more active and engaging in more verbal interaction than long-stay patients. Long-stay patients spent most of the time disengaged and isolated from contact with others.
| Norbergh, Asplund, Rassmussen, Nordahl, & Sandman (2001) | University hospital in Northern Sweden; unit for people with dementia part of the psycho-geriatric clinic N= 24 patients; MMSE mean = 11; mean Age = 79.6 years (range 62-92 years) | observational | To describe the activity of the patients’ with dementia day at a psycho-geriatric unit; explore the correlation between patients’ characteristics and time provided by nurses | Patients were monitored for 10-min intervals between 7:00am and 9:10pm | • Multi-Dimensional Dementia Assessment Scale (MDDAS) – measures vision, hearing, motor functions, ADL-functions, speech, behavioural disturbances and psychiatric symptoms  
• MMSE  
• 31% (4 h 24 min) of time with nursing staff; less than 1% (6 min) with relatives, 16% (2 h 16 min) with fellow patients and about 51% (7h 12 min) alone.  
• When alone patients were mostly walking around, resting and sleeping (5 h 45 min); alone time also included activities such as watering flowers, trying to find a nurse, looking in a paper or watching television. |
Table 4: Communication and emotion recognition

<table>
<thead>
<tr>
<th>Authors</th>
<th>Setting and sample</th>
<th>Design</th>
<th>Purpose of study</th>
<th>Effect Variables</th>
<th>Intervention</th>
<th>Measuring instruments</th>
<th>Results</th>
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</thead>
</table>
| Albert, Cohen & Koff, (1991) | N=38; 19 control (6 men; 13 women); 19 with AD (4 men, 15 women); mean age 87.5 years and 89.6 years. 725-bed long-term care facility | RCT        | “to examine the ability of mild to moderately impaired patients with AD to process emotional stimuli in greater detail” (p. 791) | Perception of affect | Participants given 9 tasks in order to do the following: 1. recognize facial emotion 2. provide verbal labels of facial emotion 3. identify emotion portrayed in drawings or in verbal descriptions of emotional situations. | Battery of standard neuropsychological tests to measure 5 different cognitive abilities: attention, language, memory, visuo-spatial function, and abstract thinking. 1. Weschsler Adult Intelligence Scale 2. Boston Naming Test 3. Delayed Recognition Span test 4. figure copying using figures from the Wechsler Memory scale 5. the similarities subtest of the Weschsler Adult Intelligence Scale. | • Significant differences between patients with AD and normal controls on all tests.  
• When adjusted for cognitive abilities, few tests still differentiate groups.  
• Deficits of those with AD on perception of affect are likely due to their cognitive deficits and not the result of a primary deficit in perception of emotion. |
| Burgio et al., (2000)    | CNAs (n = 64); residents (n=67); nursing home; mean MMSE intervention group = 13.50; mean MMSE control group = 12.94; mean age | Two-group comparison design with an intragroup comparison component; | To examine the “effects of communication skills training and the use of memory books by certified nursing assistants on verbal interactions between CNAs and | Verbal interactions | Two groups: (a) memory book intervention with a staff motivational system and (b) no-treatment control. Baseline = 1 | • Communication Skills Checklist  
• Computer-Assisted Behavioural Observation System  
• Observation of the LPNs Supervisory Activities  
• Memory Book | • Trained CNAs talked more and used positive phrases more often and gave specific instructions more often than the control group. Maintenance of CNA behaviour remained 2 |
<table>
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<tr>
<th>Study</th>
<th>Setting</th>
<th>Study Design</th>
<th>Intervention</th>
<th>Outcomes</th>
<th>Participants</th>
<th>Measures</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Cott, Dawson, Sidani, &amp; Wells (2002)</td>
<td>Long term care facility; n = 86 residents; overall age 82; MMSE = 6 (range 0-21).</td>
<td>RCT design</td>
<td>“to investigate the effects of a walking/talking program on residents’ communication, ambulation, and level of function when there were two residents to one care provider (2:1).” (p. 81)</td>
<td>Communication, ambulation, functional status</td>
<td></td>
<td>Checks</td>
<td>Residents who had the walking/talking intervention did not demonstrate a statistically significant difference in outcomes compared with those who received talk only intervention or no intervention.</td>
</tr>
<tr>
<td>Hubbard, Cook, Tester, &amp; Downs (2002)</td>
<td>Dementia Day Centre; N = 10; age range 72-95 years.</td>
<td>Ethnography</td>
<td>To explore “ways in which older people with dementia used and interpreted nonverbal behaviour within the context of social interactions” (p. 155)</td>
<td>Non-verbal communicative behaviours</td>
<td></td>
<td>Participant observation during four mornings</td>
<td>“older people with dementia used nonverbal behaviour in meaningful ways for others to interpret, and as a way of self-communication; and that they actively interpreted others’ nonverbal behaviour”</td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Participants</td>
<td>Methodology</td>
<td>Measures</td>
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<tr>
<td>Koff et al., (1999)</td>
<td>RCT</td>
<td>N= 42; 23 with AD (4 men and 19 women), mean age = 90.2 years and 19 healthy elderly controls (4 men and 15 women), mean age = 88.9 years; Long-term care facility</td>
<td>To assess the ability to recognize emotion in audiotaped voices, in drawings of emotional situations, and in videotaped vignettes displaying emotions in facial expression, gestures and body movements</td>
<td>4 different tasks were given to assess the following abilities: 1. processing emotion in nonverbal emotional vocalizations 2. processing emotion from audiotaped voices 3. processing emotion from situations portrayed in drawings 4. processing emotion from videotaped vignettes of facial expressions, gestures, and body movements.</td>
<td>- No group differences in the ability to process emotion presented via the auditory domain (nonverbal sounds i.e. crying, shrieking, speech prosody) Emotional drawings task and videotaped faces differentiated the groups with AD patients doing worse than controls. - AD patients do not have a primary deficit in the processing of emotion; their difficulties in perceiving emotion are associated with the cognitive impairments associated with AD.</td>
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<tr>
<td>Kolanowski, Litaker &amp; Catalano, (2002)</td>
<td>Single case study</td>
<td>N= 1 resident, 79 years old, medical center for veterans, English speaking, MMSE&lt; 4</td>
<td>1. to describe the self-reported mood and affective pattern 2. compare mood pattern to premorbid personality 3. determine concordance</td>
<td>Observations 3 times/day for 35 days Treatment activities organized by style of interest – e.g., for the Mood Affect</td>
<td>- Mood – Dementia Mood Picture Test - Observed affect – AARS - Premorbid personality – NEO-PI</td>
<td>- “There was concordance between self-reported mood and observed affect” (p. 28). - Mood reflected long-standing personality traits of</td>
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</table>
between self-reported mood and observed affect.

“mainstream consumers” style of interest, the activities offered were: group games (bowling or table games), tether ball game, “The Price is Right” group game, dancing, exercise to music with others, group sing along, talk on the phone or humorous videos.

For the “homebodies” style of interest activities offered would be: hang the laundry, make a birdhouse, apple peeler (make applesauce), make butter, sewing cards or quilt project, cooking project, starting seeds indoors.

extraversion and neuroticism.
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Design</th>
<th>Methodology</th>
<th>Affect</th>
<th>No intervention</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Lawton et al., (2000)</td>
<td>Not reported</td>
<td>Observational</td>
<td>descriptive</td>
<td>To test if the AARS was sensitive enough to capture intraindividual variations in people’s affective expression as they moved from one environmental context to another</td>
<td>Affect</td>
<td>No intervention 4 behaviour settings: 1. morning care 2. meal time 3. down time 4. activity time (6 observations for each context = 24 observations per subject)</td>
</tr>
<tr>
<td>Magai et al., (1996)</td>
<td>N=82; AD; mean age = 84 years; 77% female.</td>
<td>Quasi-experimental</td>
<td>2 research questions: 1. what is the quality of emotional responsivity in dementia patients? 2. How does emotional expression change from mid-to late stage dementia?</td>
<td>Emotional responsivity Emotional expression Coding behaviour during family visits</td>
<td>Emotional expression was assessed during a family visit.</td>
<td>People with AD express a range of affective emotions even in the late stage of the disease. 1/3 expressed sadness upon the departure of the relative.</td>
</tr>
<tr>
<td>Magai et al., (1997)</td>
<td>N=27 nursing home residents, mean age 84.4 years, 73% female, moderately to severely demented with 22% at stage</td>
<td>Correlation</td>
<td>To extend limited literature on the relation between premorbid aspects of personality and behavioural patterns during dementia.</td>
<td>Expressed emotion Emotion was coded during a family visit</td>
<td>N/A</td>
<td>Attachment style was found to be related to the expression of positive affect in those who were securely attached than in those.</td>
</tr>
</tbody>
</table>
5 of the Global Deterioration Scale, 52% at stage 6 and 25% at stage 7; N = 27 family members; N = 25 nurses aides

- examining premorbid attachment styles and emotion regulation patterns

(b) Feelings and Emotions Inventory
Current behavioural measures:
(a) Adult Behaviour Questionnaire
who were avoidantly attached.
Appendix B

Protocol for each case study
Identify suitable participants:
Consult with Nurse Manager, RN and RPN to suggest suitable residents and families for the study meeting inclusion criteria.

1. Invite resident and family to participate in the study
2. Informed Consent process

Group meeting will be held with PSWs to give information about the study. Opportunity for them to ask questions.

RESIDENT

IDENTIFY THE CASE TRIAD

FAMILY MEMBER

Chart review; consult RN, RPN to complete NPI; FAST

Interview family member

Interview resident if he/she is able

Personal Support Worker

Interview PSW

After the resident has given informed consent to participate, the PSW will be recruited. If the regular PSW is not interested then recruit one who is willing to be a part of the study and is familiar with the resident.

2. Informed Consent process

After the resident has given informed consent to participate, the PSW will be recruited. If the regular PSW is not interested then recruit one who is willing to be a part of the study and is familiar with the resident.

1. Invite resident and family to participate in the study
2. Informed Consent process

After the resident has given informed consent to participate, the PSW will be recruited. If the regular PSW is not interested then recruit one who is willing to be a part of the study and is familiar with the resident.

Chart review; consult RN, RPN to complete NPI; FAST

Interview family member

Interview resident if he/she is able

Arrange a time for family member to enact with resident what they described as pleasurable

Family member demonstrates pleasurable interaction – observation and videotaping

Watch video with family, research supervisor, committee members and PSW
- seek consensus on interpreting what was demonstrated as pleasurable
- complete AARS at the beginning of the interaction and following the interaction

Arrange a time for PSW to replicate pleasurable thing(s)

Observe and video tape PSW attempt to replicate – complete AARS prior to interaction and during interaction
Appendix C

Recruitment Script for RN or RPN
The RN, RPN and Nurse Manager were given this script as an example of what might be said when approaching one of the family members identified as meeting the study inclusion criteria.

Recruitment Script

“You may be interested in participating in a research study that will be happening on the unit in the upcoming months. It involves collecting information from you through an interview and also a look at some of the interactions between you and your relative (insert resident’s name) that are considered to be pleasant and pleasurable ones. If you would like more information about the study I can put you in touch with Malini Persaud, who is the doctoral student who will be conducting the research for her dissertation.”
Appendix D

Information Letters and Consent Forms
Since residents that are of interest for this study are in the later stages of dementia, this information letter is addressed to the appropriate decision maker as identified by the Substitute Decision Act of Ontario.

Title of the Research Study: Pleasure in the daily lives of people living with advanced dementia in a long-term care facility: A multiple case study approach.

Dear Sir or Madam,
This letter is to inform you of a research project to be conducted by myself for a PhD thesis in Nursing at the University of Toronto. My supervisor is Professor Dorothy Pringle of the Faculty of Nursing at the University of Toronto.

What is the purpose of the study?
The main objective of this study is to understand what creates pleasure in the daily lives of people with advanced cognitive impairment who are living in nursing homes.

When and where will the study take place?
The study will take place at the nursing home at xxxxxxxxxxxxx at a scheduled time that is convenient for the participants during the day or evening on any day of the week.

What will the resident be asked to do?
Residents who are able to answer questions will be interviewed about the things they like to do. The interviews will be audio-taped and transcribed. The interviews will occur in a private meeting room on the unit.

The resident will be videotaped on two occasions. First, residents will be observed and videotaped during a visit with a family member who has agreed to participate in the study. Second, an Interaction between the personal support worker who will participate in the study and the resident will be videotaped. The purpose for this is to learn if the things that family members do with their relative to bring about pleasure can also be done by health care workers by watching the videotapes. Permission to do the taping will be sought from you. The videotaping will occur in common areas: living room, kitchen and dining room or the resident’s room. No taping will be done in or near resident’s bathing areas, or in any other areas where privacy is an issue. The observational assessment will take about 30 minutes to complete.

Regardless of who provides approval for the resident, the resident herself or himself will still have the final right to refuse to participate if he or she indicates either verbally or non-verbally that he or she does not want to be involved. This decision can be communicated to the research team either by the resident, by a staff member, or you in case the resident does not do so by him or herself.
Information from the resident’s medical record (chart) will be collected about their age, their length of stay, their medical diagnoses, and their cognitive abilities. The Registered Nurse or Registered Practical Nurse working on the unit will be asked to complete some rating scales about the resident’s cognitive, emotional, and functional state. These tools have been chosen because they are appropriate for persons who live in residences such as your family member. The information will be supplied by staff, if permission is given by you. These measures will not require any of the resident’s time.

What are the risks and benefits of the study?
The level of risk related to the tasks the resident will have to accomplish is minimal. The potential risks are related to increased tiredness when participating in the interview or while visiting with their family member. The time of the visitation will vary but the maximum duration for observation will be one hour. There is a small risk that the video camera recording equipment will cause the resident some anxiety. The camera will be set up on a tripod whenever possible so that it is less likely to be noticed during the visit with family. Throughout this process, the wellbeing of the resident will be monitored and signs of anxiety or distress will lead to the immediate postponement of the interview or observation. After discussion with clinical staff, a second attempt to interview may take place. If anxiety persists in the resident then the interview or observation will be stopped and tried on another day. The completion of a current cognitive assessment may cause the resident to feel upset or uncomfortable with the questions. A resident will only be approached for a cognitive assessment if staff members are not able to give all of the needed information or if this information is not in the resident’s chart.

The results of this project could help identify specific pleasurable activities or things to do with residents with dementia to make sure that they have a good day.

Is the study confidential?
The decision to participate or not is voluntary. The resident will have the right to leave the study at any time without any consequences to him or herself or to the care he or she is receiving. Participants can withdraw from the study at any time without an explanation. The resident’s name will never be used. In order to ensure privacy: a number will be assigned to him/her for identification purposes. Quotes from the interviews and description of interactions will be written up and identified only by a number and never by name. All transcribed data including interviews and notes will be kept on a secure computer and access to the computer will be secured by use of specific passwords that only the researcher knows. The data collected will be kept in a locked filing cabinet at the researcher’s office at the Faculty of Nursing at the University of Toronto. Following transcription all audiotapes will be destroyed. Any information that the resident has personally shared that you wish to have discarded, will be removed from the analyses. You will be shown the videotaped segment at a follow-up appointment with the researcher and you will also be shown the interview transcribed words from the interview to make sure this says what you said.
The resident’s participation is important to the study. We hope you will agree for him or her to participate. We sincerely thank you for your interest in this study.

Please keep this information letter for your own records.

Yours sincerely,

Malini Persaud

You can contact me or my supervisor for additional information or if you have any questions about the study:

Malini Persaud
Faculty of Nursing
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Phone: (416)562-4864
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Supervisor: Dr. Dorothy Pringle
Faculty of Nursing
University of Toronto
50 St. George Street, Rm. 218
Toronto, Ontario
M5S 3H4 Canada
Phone: (416)978-2068
Fax: (416) 978-8222
Email: Dorothy.pringle@utoronto.ca
Informed Consent Form
(Appropriate decision maker)

Research Project Title: Pleasure in the daily lives of people living with advanced dementia in a long-term care facility: A multiple case study approach.

Researcher: Malini Persaud
Phone: (416)562-4864

This consent form is only part of the process of informed consent. You will get a copy of this letter. It should give you a general idea of what the research is about and what you will be asked to do. If you would like more information about something that you read in the letter or if you did not find some details you were wondering about, feel free to ask. Please take the time to read and understand this carefully.

Since residents are in the later stages of dementia, this information letter is addressed to the appropriate decision maker as identified by the Substitute Decision Act of Ontario.

I, __________________________, undersigned, accept that the resident __________________ participate in this PhD thesis study as described in the information letter. The main objective of the study is to explore how pleasure is created in the lives of people with advanced dementia who live in long-term care facilities.

I have received and carefully read the information letter and understand that the above named resident will be interviewed (if able) by the researcher. The interview will be audio-taped and will last about 30 minutes. The interview will take place in a quiet and private room located on the unit. I understand that the resident will also be included in videotaping of interactions between his or her family member during a visit. The videotaped observed family member visit will last about one hour. The resident will be videotaped again during an interaction with a personal support worker who is part of the study and who the resident is familiar with. The health care provider videotaped observation will last 30 minutes. Videotaping will occur in common areas: living room, kitchen and dining room or the resident’s room. No taping will be done in or near residents’ bathing areas or during private care such as getting dressed. Even though I may have initially consented to the video-taping and audio-taping, I or the resident, can indicate that the video or audio taping be stopped or that I wish to withdraw my original consent. At all times my or the resident’s wishes will be carried out.

I understand that all other data will be obtained through chart reviews and consultation with the nursing staff. The resident will have a series of standardized tests completed by staff on the resident’s cognitive, functional, and emotional status. I also understand that if the resident communicates in one manner or another that he or she does not want to participate that he/she will be withdrawn from the study with no consequences to current or future care received at the facility.
I understand that the results of this study will only be used for the needs of this research project. The tapes and transcripts will not have my relative’s name or other identifiable information on them. A research assigned code will be used instead. I understand that all data will be kept on a password protected laptop computer. The videotapes will be stored in a locked cabinet for which only the researcher has a key. No information will be printed with identifiable information on it.

The possible risks and possible discomfort associated to these tasks have been explained to me. I have asked all the questions I had regarding this subject and I am satisfied with the answers given to me. I, or the resident, have the right to withdraw from this study at any time and without any effects to the care the resident is receiving.

I have received a copy of the information letter and consent form.

Name of resident:_____________________________________________
Name of appropriate decision maker:_____________________________
Signature of appropriate decision maker:____________________ Date: __________

I have described the study to the appropriate decision maker and insured he or she is aware of the involved consequences.

Signature: ___________________________________________
Title: _____________________________ Date: _______________

You can contact me or my supervisor for additional information or if you have any questions about the study:

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Supervisor: Dr. Dorothy Pringle
Faculty of Nursing
University of Toronto
50 St. George Street, Rm. 218
Toronto, Ontario
M5S 3H4 Canada
Phone: (416)978-2068
Fax: (416) 978-8222
Email: Dorothy.pringle@utoronto.ca
Dear Sir or Madam,

This letter is to inform you of a research project to be conducted by myself for a PhD thesis in Nursing at the University of Toronto. My supervisor is Professor Dorothy Pringle of the Faculty of Nursing at the University of Toronto.

What is the purpose of the study?
The main objective of this study is to understand what creates pleasure in the daily lives of people with advanced cognitive impairment who are living in nursing homes. We are interested in whether things that family members do with their relatives that relatives seem to enjoy are enjoyable when they are done with a member of the nursing staff.

When and where will the study take place?
The study will take place at the nursing home at xxxxxxxxxxxx at a scheduled time that is convenient for the participants during the day or evening on any day of the week.

What will I be asked to do?
You will be interviewed by the researcher. The questions you will be asked are about what you think helps the residents you care for enjoy themselves and what things you look for to help you know they are enjoying themselves. The interviews will be audio-taped and then the words will be typed out to produce a transcript. The interviews will take place in a private meeting room on the unit. You will be given a copy of the interview transcript to make sure that it says what you mean to say. You may withdraw your consent to be interviewed at any time without an explanation or consequences. You will be asked to answer a few questions at the start of the interview about yourself including your professional designation, number of hours you work and the length of time you have worked at the home and your age range.

You will also be asked to watch a videotaped recording of the resident and his or her family member interacting. While you are watching the video tape, the researcher will point out parts of the video tape that the family member and the researcher feel show pleasure in the resident. You will be asked to learn this strategy and practice as much as you would like until you feel comfortable that you and the resident are able to do them together. When you are ready you and the resident will be videotaped doing the same things as the resident did with his/her family member. This will not last more than one hour. You will be shown the videotape to make sure that it shows what you wanted to demonstrate as pleasurable to the resident that you had practiced from watching the tapes with the family earlier. I will ask for your permission to do the videotaping.
videotaping will occur in these areas: living room, kitchen and dining room or the resident’s room. No video taping will be done in or near resident’s bathing areas, or in any other areas where privacy is an issue. You may withdraw your consent to be videotaped at any time without an explanation.

What are the risks and benefits of the study?
The level of risk related to the tasks you will be asked to do is very small. There is a small risk that the video camera recording equipment may make you feel self-conscious or nervous. The camera will be set up on a tripod stand whenever possible so that you don’t notice it as much during your time with the resident.

The results of this project could help me to learn some things or activities that make residents feel happy, joyful and interested. This will help them to have a good day.

Will I be compensated for my time?
If you spend extra time on the unit outside of your regularly scheduled shift to participate in this study, you will be paid at your regular hourly rate of pay by the researcher.

Is the study confidential?
The choice to participate or not is voluntary. You can leave the study at any time without an explanation. Your name will never be used in order to preserve complete privacy. A number will be assigned to you so that none of the typed up notes from my interview with you will have your name on them. All of the notes that I collect from our interview will be kept on a safe computer and access to the computer will be secured by a specific password that nobody except me knows. The videotapes will be kept in a locked filing cabinet at my office at the Faculty of Nursing at the University of Toronto. After the notes are typed up from the taped interview all of the audiotapes will be destroyed. If at any time while we are talking during the interview, you feel you have said something that you don’t want to be used for the study, I will take that part out when I type the notes.

What will this information be used for?
Some of the things you tell me in the interview and my own written description of your interactions with the resident from the videotape will be written up. I will give talks about the study at professional meetings and articles will be published in professional journals. Your name will never be used in these talks and articles.

Your participation is important in helping us to understand pleasure in the lives of people with advanced dementia. Thank you for your interest in this study.

Please keep this information letter for your own records.
Yours sincerely,
Malini Persaud
You can contact me or my supervisor for additional information or if you have any questions about the study:

Malini Persaud  
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**Supervisor:** Dr. Dorothy Pringle  
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University of Toronto  
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**Phone:** (416)978-2068  
**Fax:** (416) 978-8222  
**Email:** Dorothy.pringle@utoronto.ca
Research Project Title: Pleasure in the daily lives of people living with advanced dementia in a long-term care facility: A multiple case study approach.

Researcher: Malini Persaud  Phone: (416)562-4864

This consent form is only part of the process of informed consent. You will get a copy of this letter. It should give you a general idea of what the research is about and what you will be asked to do. If you would like more information about something that you read in the letter or if you did not find some details you were wondering about, feel free to ask. Please take the time to read and understand this carefully.

I, __________________________, understand that Malini Persaud is conducting this study for her PhD thesis as described in the information letter. The main objective is to explore how pleasure is created in the lives of people with advanced dementia who live in long-term care facilities.

I have received and carefully read the information letter and understand I will be interviewed by the researcher. The interview will be audio-taped and will last about 30 minutes. The interview will take place in a quiet and private area on the unit. I understand that the resident and I will be included in videotaping of interactions together. This will last no more than one hour. Videotaping may take place in the following areas: living room, kitchen and dining room or the resident’s room. No taping will be done in or near residents’ bathing areas or during private care such as dressing. Even though I may have initially said yes to the video-taping and audio-taping, I can indicate at any time that the video or audio taping be stopped or that I do not wish to be in the study anymore.

I understand that the results of this study will only be used for the needs of this research project. The videotapes and interview transcripts will not have my name or other identifiable information on them. A code number will be used instead. I understand that all information will be kept on a password protected laptop computer. The videotapes will be stored in a locked cabinet for which only Malini Persaud has a key. No information will be printed with my name on it.

The small possible risks associated to these tasks have been explained to me. I have asked all the questions I had about this study and I am satisfied with the answers given to me. I have the right to leave this study at any time and without any effects on my job.

I got a copy of the information letter and the consent form.

I hereby consent to participate in this study.

Date: __________________________

Participant: __________________________

Researcher: __________________________
You can contact me or my supervisor for additional information or if you have any questions.

Malini Persaud                      Supervisor: Dr. Dorothy Pringle
Faculty of Nursing                  Faculty of Nursing
University of Toronto               University of Toronto
50 St. George Street                50 St. George Street, Rm. 218
Toronto, Ontario                    Toronto, Ontario
M5S 3H4 Canada                      M5S 3H4 Canada
Phone: (416)562-4864                Phone: (416)978-2068
Fax: (416)752-3273                  Fax: (416) 978-8222
Email: malini.persaud@utoronto.ca    Email: Dorothy.pringle@utoronto.ca
Study Information Letter
(family member)

Title of the Research Study: Pleasure in the daily lives of people living with advanced dementia in a long-term care facility: A multiple case study approach.

Dear Sir or Madam,
This letter is to inform you of a research project to be conducted by myself for a PhD thesis in Nursing at the University of Toronto. My supervisor is Professor Dorothy Pringle of the Faculty of Nursing at the University of Toronto.

What is the purpose of the study?

The main objective of this study is to understand what creates pleasure in the daily lives of people with advanced cognitive impairment who are living in nursing homes.

When and where will the study take place?

The study will take place at the nursing home at a scheduled time that is convenient for the participants during the day or evening on any day of the week.

What will I be asked to do?

You will be interviewed about your relative’s past preferences and hobbies. The interviews will be audio-taped and then transcribed. The interviews will occur in a private meeting room. You will be given a copy of the interview transcript to review that it accurately reflects the conversation you had with the interviewer. Audiotapes will be destroyed after transcription. You may withdraw your consent to be interviewed at any time without an explanation or repercussions to you or your relative. You will be asked to complete a short questionnaire at the start of the interview about yourself including your age range, gender, relationship to the resident and how often you visit. The questionnaire will take about 5 minutes to complete.

You will also be asked to demonstrate things that you do to create pleasure in your family member during a scheduled visit at the nursing home. The visit will be observed and videotaped for a maximum of one hour. You will be shown the videotape to verify that it has captured what you intended to demonstrate as pleasurable to your relative. A personal support worker that has agreed to participate in the study and whom your relative is familiar with will be shown the videotape. The purpose for this is to learn if the things that family members do with their relative to bring about pleasure can also be done by health care workers by watching the videotapes. Permission to do the taping will be sought from you. The videotaping will occur in the following areas: living room, kitchen and dining room or the resident’s room. No taping will be done in or near resident’s
bathing areas, or in any other areas where privacy is an issue. You may withdraw your consent to be videotaped at any time without an explanation. Participation in this study is voluntary.

**What are the risks and benefits of the study?**

The level of risk related to the tasks you will be asked to do is minimal. The potential risks are related to increased emotional feelings while reminiscing about your relative’s past preferences and focusing on his or her current abilities. There is a risk that the video camera recording equipment may cause you to feel self-conscious or nervous. The camera will be set up on a tripod whenever possible so that it is minimally obstructive to the visit with your relative.

The results of this project could help identify specific pleasure inducing activities or approaches among residents with dementia and promote their daily quality of life.

**Is the study confidential?**

The decision to participate or not is voluntary. You can withdraw from the study at any time without an explanation. Your name will never be used in order to preserve complete anonymity: a random number will be assigned to you for identification purposes. This number will be on the questionnaire, the interview transcripts and the videotapes. Quotes from the interviews and description of interactions will be written up. All transcribed data including interviews and field notes will be kept on a secure computer and access to the computer will be secured by use of specific passwords known only to the researcher. The data collected will be kept in a locked filing cabinet at the researcher’s office at the Faculty of Nursing at the University of Toronto. Following transcription all audiotapes will be destroyed. Any information that you have personally shared that you wish to have taken out, will be removed from my analyses. No information will be released or printed that would disclose your personal identity. You will be shown the videotaped segment at a follow-up appointment with the researcher and you will also be shown the interview verbatim transcript for verification and accuracy of the researcher’s interpretations.

The results will be written up in professional journals and presentation at professional meetings will be done at the end of the study.

Your participation is important in furthering our understanding about pleasure in the lives of people with advanced dementia. Thank you for your interest in this study.

Please keep this information letter for your own records.

Yours sincerely

Malini Persaud
You can contact me or my supervisor for additional information or if you have any questions about the study:

Malini Persaud  
Faculty of Nursing  
University of Toronto  
50 St. George Street  
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**Phone:** (416)562-4864  
**Fax:** (416)752-3273  
**Email:** malini.persaud@utoronto.ca

**Supervisor:** Dr. Dorothy Pringle  
Faculty of Nursing  
University of Toronto  
50 St. George Street, Rm. 218  
Toronto, Ontario  
M5S 3H4 Canada  
**Phone:** (416)978-2068  
**Fax:** (416) 978-8222  
**Email:** Dorothy.pringle@utoronto.ca
Informed Consent Form

Research Project Title: Pleasure in the daily lives of people living with advanced dementia in a long-term care facility: A multiple case study approach.

Researcher: Malini Persaud    Phone: (416)562-4864

This consent form is only part of the process of informed consent. You will get a copy of this letter. It should give you a general idea of what the research is about and what you will be asked to do. If you would like more information about something that you read in the letter or if you did not find some details you were wondering about, feel free to ask. Please take the time to read and understand this carefully.

I, _______________________, understand that Malini Persaud is conducting this PhD thesis study as described in the information letter whose main objective is to explore how pleasure is created in the lives of people with advanced dementia who live in long-term care facilities.

I have received and carefully read the information letter and understand I will be interviewed by the researcher. The interview will be audio-taped and will last about 30 minutes. The interview will take place in a quiet and private room located in the same building. I understand that the resident and I will be included in videotaping of interactions during a visit. This videotaped observed visit will last about one hour. Videotaping will occur in the following areas: living room, kitchen and dining room or resident’s room. No taping will be done in or near residents’ bathing areas or where privacy is an issue. Even though I may have initially consented to the video-taping and audio-taping, I can indicate at any time that the video or audio taping be stopped or that I wish to withdraw my original consent.

I understand that the results of this study will only be used for the needs of this research project. The videotapes and interview transcripts will not have my relative’s name or other identifiable information on them. A research assigned number will be used instead. I understand that all data will be kept on a password protected laptop computer. The videotapes will be stored in a locked cabinet for which only the researcher has a key. No information will be printed with identifiable information on it.

The small risks associated with the study have been explained to me. I have asked all the questions I had about this subject and I am satisfied with the answers given to me. I have the right to leave this study at any time without any consequences neither to me nor to the care the resident is receiving.

I have gotten a copy of the information letter and consent form.
I hereby consent to participate in this study.

Date: _____________________________________________________

Participant:  ________________________________________________
Researcher: ________________________________________
You can contact me or my supervisor for additional information or if you have any questions about the study:

Malini Persaud  
Faculty of Nursing  
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Supervisor: Dr. Dorothy Pringle  
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Fax: (416) 978-8222  
Email: Dorothy.pringle@utoronto.ca
Appendix E

Interview Guides
Interview Guide for Resident

Remind the resident about the research study and why you are interviewing them today. Tell the resident that the interview will be tape recorded and transcribed afterwards.

*Key Questions for Residents: Prompt (if necessary)

**Opening**
1. Hello my name is Malini. I am a nurse.

**Introduction**
2. How are you doing Mr. ____ or Mrs. _____

**Transition**
3. Today I will ask you some questions about the things you like to do

**Key**
4. Is today a good day for you? How was your day today?

Key 5. What do you like to do? Arts and crafts, games (bingo), music concert, going for a walk, pets

Key 6. Do you have any hobbies? Things you like to do, are interested in, like playing cards, listening to music

**Key**
7. What makes you feel happy?

**Key**
8. What do you like to do with your family when they come to visit you?

**Ending**
9. Thank you for your time, I will be seeing you again when you visit with your family member (insert name).

*(Santo Pietro, & Ostuni, 2003)*
Interview Guide for family caregiver

Explain that the purpose of the research is to gain an understanding of both strategies used to create pleasure and indicators of positive affect in residents.

Key Questions for family caregivers: Prompts (if necessary)

Opening

1. Prior to moving to [nursing home], did your _______ (insert family member’s name/title, i.e. mother, wife) live with you at home?

2. Tell me what that was like just before s/he came to live at _________?

Introduction

3. How often are you able to visit? What keeps you away from visiting? What keeps you coming to visit?

Transition

4. Do you attend any of the recreational activities with your relative (insert family member’s name/title)

Key

5. What were the things that your _______ (insert family member’s name/title) enjoyed in the past? For example: did they attend to music, really loved playing with grandchildren; gardening; going out….

Key

6. How would you describe _______ personality now compared to his/her past personality?

Key

7. As cognitive impairment increased what were you able to do with them that they enjoyed? Enjoyable; pleasurable; made them seem happy - can you give me an example

Key

8. When you come for a visit now, how do you know what to do with your relative? Cues you take from resident? Can you give me an example?
Key 9. How do you know what they need? Do you simply ask them? How do you ask them? e.g. With words, by showing various pictures of choices, by initiating the activity and watching for approval/participation on their part

Key 10. How do you know if they are enjoying something with you? Indicators i.e. things you look for, things you see
- explain further
11. What signals or indicators do you look for? - give me an example

Key 12. What strategies do you use to bring about pleasure in your ______ (insert family member’s name/title)? If the person says they have none and need help in this regard, suggest the Recreational Therapist or the RN on the unit as resources (field note to follow up) Ask them if they have sought help/advice from others, professional or non professional.

Ending 13. As you know, we are trying to learn about pleasurable experiences, is there anything you would like to add to what you have already shared with me?
Appendix F

Careprovider Demographic Profiles
Careprovider Demographic Profile

Identification Number: ____________  Date: ______________

The researcher will ask the following questions to the PSW at the beginning of the interview.

1. What is your highest level of education?
   a. Public school completion
   b. Some high school education
   c. High School Diploma
   d. Some community college education
   e. Community College Diploma
   f. Some university education
   g. Bachelors Degree
   h. Graduate School
   Other, Please Specify ______________________

2. How many years have you worked at xxxxxxx?
   a. Less than 1 year, number of months ___________
   b. 1-3 years
   c. 4-10 years
   d. more than 10 years

3. Are you currently working
   a. Full-time (37 hours per week)
   b. Part-time (20 hours per week)
   c. Casual , Please Specify number of hours per week _____________

4. What is your gender?
   a. Female
   b. Male

5. What is your present age range?
   a. 19-25
   b. 26-35
   c. 36-45
   d. 46 – 55
   e. over 56
Family Member Demographic Profile

Identification Number: ____________   Date: ________________

The researcher will ask the following questions to the family member at the beginning of the interview.

1. What is your highest level of education?
   a. Public school completion
   b. Some high school education
   c. High School Diploma
   d. Some community college education
   e. Community College Diploma
   f. Some university education
   g. Bachelors Degree
   h. Graduate School
   Other, Please Specify ______________________

2. How many times per week do you visit your relative at xxxxxx?
   a. Once weekly
   b. Twice weekly
   c. More than twice weekly, please indicate how many times ________
   d. Daily
   e. 

3. What is the average length of time you spend with your relative while visiting?
   a. Less than 30 minutes per visit
   b. 30 to 60 minutes per visit
   c. more than 1 hour per visit

4. What is your gender?
   c. Female
   d. Male

5. What is your present age range?
   a. 19-25
   b. 26-35
   c. 36-45
   d. 46 – 55
   e. 56 – 65
   f. over 65
Appendix G

Assessment Tool Results
## Assessment Tool Scores

<table>
<thead>
<tr>
<th>Name of Resident</th>
<th>1NPI (over past month)</th>
<th>2MMSE</th>
<th>3FAST</th>
<th>4AARS</th>
<th>5AAI (Social subscale)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emma</td>
<td>Mild agitation</td>
<td>None on chart, Did not assess</td>
<td>7a</td>
<td>Pleasure 5 = &gt;2min. Interest 5 = &gt;2min.</td>
<td>Total 10/29 = 34%</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Apathy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Irritability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mary</td>
<td>Mild anxiety</td>
<td>16 (February 2006, from chart)</td>
<td>6b</td>
<td>Pleasure 4 = 1-2 min. Interest 5 = &gt;2 min.</td>
<td>24/29 = 83%</td>
</tr>
<tr>
<td></td>
<td>Elation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disinhibition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Irritability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Slight loss of appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anne</td>
<td>Moderate depression</td>
<td>Unable to assess None on chart</td>
<td>7e</td>
<td>Pleasure 9 = Can’t tell Interest 2 = &lt;16 sec.</td>
<td>2/29 = 7%</td>
</tr>
<tr>
<td>Isa</td>
<td>Mild agitation</td>
<td>1 (2002)</td>
<td>7d</td>
<td>Pleasure 9 = Can’t tell Interest 9 = Can’t tell</td>
<td>0/29</td>
</tr>
<tr>
<td></td>
<td>Apathy</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marjie</td>
<td>Mild apathy</td>
<td>Unable to assess None on chart</td>
<td>7b</td>
<td>Pleasure 2 = &lt;16 sec. Interest 3 = 16-59 sec.</td>
<td>8/29 = 28%</td>
</tr>
<tr>
<td>Sylvia</td>
<td>Mild depression</td>
<td>11 (March 2000)</td>
<td>7a</td>
<td>Pleasure 5 = &gt;2 min. Interest 3 = 16-59 sec.</td>
<td>16/29 = 56%</td>
</tr>
<tr>
<td></td>
<td>Wanders occasionally</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Moderate euphoria</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sammy</td>
<td>Mild delusions</td>
<td>14 (2002)</td>
<td>7a</td>
<td>Pleasure 3 = 16-59 sec. Interest 4 = 1-2 min.</td>
<td>19/29 = 66%</td>
</tr>
<tr>
<td></td>
<td>Disinhibition</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Moderately depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severely agitated</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Anxious</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Irritable</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1NPI – Neuropsychiatric inventory; 2MMSE – Mini Mental State Exam; 3FAST – Functional Assessment Staging Test; 4AARS – Apparent Affect Rating Scale; 5AAI – Abilities Assessment Inventory (social subscale)
Appendix H

Transcription Notation Table
<table>
<thead>
<tr>
<th><strong>Symbol</strong></th>
<th><strong>Meaning</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Pauses (…)</td>
<td>Denote short pauses during talking by a series of dots (…), the length of which depends on the amount of time elapsed (e.g., two dots for less than half a second, three dots for one second, four dots for one and a half seconds)</td>
</tr>
<tr>
<td>“(Pause)”</td>
<td>Denote longer pauses with the word pause in parentheses</td>
</tr>
<tr>
<td>“(laughing)”</td>
<td>Laughing, coughing, etc. Indicate in parentheses</td>
</tr>
<tr>
<td>“(coughs)”</td>
<td></td>
</tr>
<tr>
<td>“(sighs)”</td>
<td></td>
</tr>
<tr>
<td>-</td>
<td>Use a hyphen to indicate interruptions to speech, when someone’s speech is broken off mid-sentence by including (-)</td>
</tr>
<tr>
<td>“(overlapping)”</td>
<td>Use a hyphen to indicate where the previous speaker interjected and the term overlapping</td>
</tr>
<tr>
<td>[Garbled speech?]</td>
<td>Flag words that are unclear with a ? and square brackets, in the square bracket write the word you think the person has said followed by a question mark</td>
</tr>
<tr>
<td>EMPHASIS</td>
<td>Use caps to denote strong emphasis, boldface or underlining is not formatted in some qualitative software packages.</td>
</tr>
</tbody>
</table>
Appendix I

Videotape analysis
Videotape Analysis

- Video record interaction between family member & person with dementia

Malini watches video several times

Malini & supervisor watch the video several times

Malini & Family member who was videoed watch the video together (verification)

Show videotaped segment to PSW

- Video record interaction between PSW & person with dementia

Malini watches video several times

Malini & Supervisor Watch the Video several times

Malini & PSW who was videoed watch the video together (verification)

Malini books a follow up appointment with family

Malini books appointment with PSW

Coding - AARS

Intercoder reliability

Final Coding template developed

Coding - AARS

Coding - AARS

Intercoder reliability
Appendix J

Retrogenesis Table
Table 1. Functional landmarks in normal human development and Alzheimer's disease*

<table>
<thead>
<tr>
<th>Developmental age</th>
<th>Approximate age</th>
<th>Approx. duration in Development</th>
<th>Acquired abilities</th>
<th>Lost abilities</th>
<th>Alzheimer stage</th>
<th>Approx. duration in AD</th>
<th>Developmental age of patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescence</td>
<td>13 – 19 yrs</td>
<td>7 yrs</td>
<td>hold a job</td>
<td>hold a job</td>
<td>3</td>
<td>7 yrs</td>
<td>19 – 13 yrs (adolescence)</td>
</tr>
<tr>
<td>Late Childhood</td>
<td>8 – 12 yrs</td>
<td>5 yrs</td>
<td>handle simple finances</td>
<td>handle simple finances</td>
<td>4</td>
<td>2 yrs</td>
<td>12 – 8 yrs (late childhood)</td>
</tr>
<tr>
<td>Middle childhood</td>
<td>5 – 7 yrs</td>
<td>2½ yrs</td>
<td>select proper clothing</td>
<td>select proper clothing</td>
<td>5</td>
<td>1½ yrs</td>
<td>7 – 5 yrs (middle childhood)</td>
</tr>
<tr>
<td>Early childhood</td>
<td>5 yrs</td>
<td>4 yrs</td>
<td>- put on clothes unaided</td>
<td>- put on clothes unaided</td>
<td>6a</td>
<td>2½ yrs</td>
<td>5 – 2 yrs (early childhood)</td>
</tr>
<tr>
<td></td>
<td>4 yrs</td>
<td></td>
<td>- shower unaided</td>
<td>- shower unaided</td>
<td>b</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 – 4½ yrs</td>
<td></td>
<td>- toilet unaided</td>
<td>- toilet unaided</td>
<td>c</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 – 3 yrs</td>
<td></td>
<td>- control urine unaided</td>
<td>- control urine unaided</td>
<td>d</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- control bowels</td>
<td>- control bowels</td>
<td>e</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Infancy</td>
<td>15 mo</td>
<td>1½ yrs</td>
<td>- speak 5-6 words</td>
<td>- speak 5-6 words</td>
<td>7a</td>
<td>7 yrs</td>
<td>15 mo – birth (infancy)</td>
</tr>
<tr>
<td></td>
<td>1 yr</td>
<td></td>
<td>- speak 1 word</td>
<td>- speak 1 word</td>
<td>b</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 yr</td>
<td></td>
<td>- walk</td>
<td>- walk</td>
<td>c</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 – 10 mo</td>
<td></td>
<td>- sit up</td>
<td>- sit up</td>
<td>d</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 – 4 mo</td>
<td></td>
<td>- smile</td>
<td>- smile</td>
<td>e</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 – 3 mo</td>
<td></td>
<td>- hold up head</td>
<td>- hold up head</td>
<td>f</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appendix K

Retrogenesis Applied to Residents
<table>
<thead>
<tr>
<th>Case Study: Resident</th>
<th>FAST&lt;sup&gt;1&lt;/sup&gt; stage</th>
<th>Indicators of Pleasure</th>
<th>Pleasurable Things</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mary</td>
<td>6b</td>
<td>Holding hands, smiling; laughing; singing</td>
<td>Going for a walk off the unit with daughter; reminiscing; singing, conversations about family</td>
</tr>
<tr>
<td>Emma</td>
<td>7a</td>
<td>Smiling; Laughing; posing for camera</td>
<td>Dancing, playing cards, holding hands, chatting, lying down on the bed, having make-up applied, having nails polished, being given praise and compliments</td>
</tr>
<tr>
<td>Sylvia</td>
<td>7a</td>
<td>Smiling; holding hands; posing for camera; nodding; laughing.</td>
<td>Sitting in living room area just before lunch; sitting together during lunch</td>
</tr>
<tr>
<td>Sammy</td>
<td>7a</td>
<td>Sense of humour; paying compliments; interest in talking about going fishing; going out dancing Singing; holding hands; smiling; flirting.</td>
<td>Visited with father in room and chatted about fishing, reminisced about family, sang together, chatted, and talked about pictures in room.</td>
</tr>
<tr>
<td>Marjie</td>
<td>7b</td>
<td>Laughing; smiling; eating ice-cream; dancing to music.</td>
<td>Going for a walk off the unit; sitting in coffee shop having ice-cream</td>
</tr>
<tr>
<td>Isa</td>
<td>7d</td>
<td>More relaxed facial expression, slight smile; holding hands; lip smacking while eating.</td>
<td>Music; sweets; touch; presence</td>
</tr>
<tr>
<td>Anne</td>
<td>7e</td>
<td>Slight change in facial expression; tightening grasp; opening mouth for sweet foods.</td>
<td>Music; sweets; touch; presence</td>
</tr>
</tbody>
</table>

<sup>1</sup>Functional Assessment Staging Test (FAST), (Reisberg, 1988).

*“retrogenesis is the process by which degenerative mechanisms reverse the order of acquisition in normal development”* (Reisberg et al., 2002, p. 202)