

**Cognitive Limitations and Social Abilities Among  
Female Residents in Long-Term Care With A  
Progressive Dementia**

By  
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A Thesis  
Submitted to the Faculty of Graduate Studies

In Partial Fulfillment of the Requirements of the Degree of  
Master of Nursing

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**Cognitive Limitations and Social Abilities among Female Residents in  
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**BY**

**Barbara Tallman**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements of the degree  
of**

**MASTER OF NURSING**

**BARBARA TALLMAN ©2002**

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## ABSTRACT

The purpose of this research was to develop a greater understanding of the relationship between cognitive limitations and social ability among long-term care residents with a progressive dementia. The Disablement Model guided the examination of the relationship between these factors. The model describes the factors that impact the degree to which a disease process affects the abilities of an individual to engage in day to day activities. The research was cross-sectional with a convenience sample of 35 long-term care residents with a progressive dementia. The settings were personal care facilities in Winnipeg, Manitoba, Canada. Data were collected using face-to-face interviews with residents and through chart retrieval. Cognitive limitations were measured using the Dementia Rating Scale (DRS) and a facial affect recognition item (FA) from the Abilities Assessment Inventory developed to measure abilities of individuals with a dementia. Social abilities were measured using the Social Abilities Subscale (SAS). Helping ability was measured by an item that was developed for this research to examine the ability of individuals with a progressive dementia to provide support for others. Sociodemographic information as well as information on behaviour, activities of daily living and health were collected. Univariate statistical approaches were used to describe the characteristics of participants in the research. Bivariate statistical approaches were used to describe the relationship between cognitive limitations and social ability. The findings from the data analysis indicate that there was an association between cognitive limitations and social ability. There was a statistically significant relationship between the DRS and the SAS ( $\rho=.644$ ,  $p<.01$ ) and between FA and SAS ( $\rho=.429$ ,  $p<.05$ ). There was a statistically



significant relationship between the DRS and the helping item. There was no statistically significant association between the FA and the helping item. This research contributes to both theoretical and clinical domains of issues affecting the assessment and care of individuals with a progressive dementia.

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## **CHAPTER 1**

### **Statement of the Problem**

People with dementia suffer from a progressive loss of cognitive abilities that profoundly affects their everyday activities, independence and quality of life.

Approximately 8% of Canadians age 65 and older have some form of dementia and the prevalence increases to 33% for individuals age 85 and older (Canadian Study of Health and Aging, 1994). Individuals aged 85 and older are referred to as the "old-old" and are a rapidly growing segment of the Canadian population. This projected trend suggests an increase in the number of individuals with dementia. In long-term care facilities, estimates indicate that at least 80% of residents suffer from dementia and the vast majority have Alzheimer's type dementia (a progressive dementia) (AD) (Hofland, 1994, Mega & Cummings, 1996). In these settings the provision of quality of life requires that clinicians recognize the positive behaviours that continue in individuals with AD.

The opportunity to express positive social behaviour through meaningful social interactions is identified as a significant factor in the quality of life of people residing in nursing homes (Aller & Coeling, 1995, Guse & Masesar, 1999, Oleson, Togerud, Bernette, Steiner & Odiet, 1998). For individuals with AD, the lack of recognition of social ability can limit these opportunities.

Research suggests that individuals with AD maintain their social abilities despite cognitive limitations (Albert, Cohen & Koff, 1991). Inappropriate clinical decisions can be made based on clinician's lack of understanding of the social capabilities of the individual with AD. For example, the clinician might miss the cognitive deficits that put

the individual at risk because of these individuals' ability to engage appropriately in social interaction. As another example, the clinician can neglect engaging the individual in social interaction because he/she is unaware of this retained social ability. Without social stimulation, the individual with AD can become isolated which might in turn lead to frustration and an increase in troublesome behaviour. These concerns have been raised in the literature (Kitwood, 1997). Research on the relationship between cognition and social ability that facilitates broader insight into the capacities of individuals with AD is needed.

This research examined the relationship between cognitive limitations and social ability of residents with AD. This chapter provides an overview of dementia and AD, describes dementia and quality of life in long-term care, introduces the conceptual model and presents the research questions.

### **1.1 Dementia and Alzheimer's Type Dementia**

The World Health Organization provides the following definition of dementia:

"Dementia is the global impairment of higher cortical functions, including memory, the capacity to solve problems of day to day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions in the absence of gross clouding of consciousness." (cited in Keady, 1996, p.276).

Although several types of dementia exist, the two major types are Alzheimer's type dementia (AD) and Vascular type dementia (VaD). The most common form is AD and approximately 80% of individuals with dementia are identified as having AD (Canadian Study of Health and Aging, 1994). The criteria for establishing a diagnosis of probable AD includes the following:

1. Dementia present
2. Onset between 40 and 90 years of age
3. Deficits in two or more cognitive areas
4. Progression of deficits
5. Consciousness undisturbed
6. Absence of other reasonable diagnosis. (McKhann et al., 1984)

The criterion that distinguishes a diagnosis of Alzheimer's type Dementia from VaD is the progressive loss of cognitive abilities. When individuals are in a personal care home due to a progressive dementia and there are no other identified causes for the dementia (such as stroke, Korsokoff's syndrome or Parkinson's) it is likely an Alzheimer's type Dementia. The features of this diagnosis include increases in cognitive and social dysfunction (Ashford, Schmitt & Kumer, 1998). Changes in social function are marked by difficulties in coping with everyday activities. The extent to which the individual experiences difficulties with social function and the cognitive limitations defines the extent of the disease process. Reisberg's (1988) Functional Assessment Staging Tool, (FAST) is a method commonly used clinically to describe the stage of dementia. The stages are as follows: stage 1 is no deficits, stage 2 is subjective complaints of memory deficits, stage 3 is the earliest evidence of objective memory deficit with intensive interview, stage 4 is clear cut deficit on careful interview, stage 5 is the inability to survive without some assistance, stage 6a) is the inability to dress properly without assistance, 6b) is the inability to bathe properly, 6c) is the inability to handle the mechanics of toileting, 6d) is urinary incontinence, and 6e) is fecal incontinence. In



stage 7, there is reduction in the ability to speak, walk, sit properly, smile and hold one's head up (Reisberg, 1988).

This research included people with a progressive dementia who are in stages 5 or 6 and who typically reside in long-term care facilities. Stages 5 and 6 are often described as moderate or severe dementia (Ashford et al, 1999). Individuals with moderate or severe dementia are still capable of responding to simple questions and statements.

### **1.2 Dementia and Quality of Life in Long Term Care**

Promoting quality of life for individuals with a progressive dementia in long-term care settings goes beyond providing custodial care. Promoting quality of life means providing individuals with a progressive dementia an opportunity for meaningful social interactions including the opportunity to be helpful to others (Aller & Coeling, 1995, Guse & Masesar, 1999). The capacity to engage in social interaction remains for all but the most severely cognitively impaired individuals (Stage 7). If the capacity to interact is not recognized and supported by formal caregivers, quality of life will be diminished (Kitwood, 1997). Lacking social stimulation residents with a progressive dementia may lose at an accelerated pace, their capacity to socially interact with others (Dawson et al., 1993).

Beck and Heacock (1988) suggest that quality of care for individuals with dementia begins with a thorough assessment of the relationship between cognition and behaviour. A necessary step in the provision of quality care is that caregivers recognize subtle and discrete cues of optimal behaviour of the individual with AD (Dawson, Kline, Wiancko & Wells, 1986, Kelly, 1997, Ryan, Meridith & Maclean, 1995). Research that

examines the relationship between the cognition and social abilities of residents with AD could contribute to caregivers' understanding and enhancement of social abilities (Dawson et al., 1993). Encouraging social skills can exercise cognitive skills such as memory and recall, bring a sense of purpose to a resident with AD and can positively affect the expectations of others who interact with residents (Oleson, Togerud, Bernette, Steiner & Odiet, 1998).

### **1.3 The Disablement Model**

Conceptual models that depict the relationship between cognition and social ability are not apparent. The Disablement Model (Guralnik, 1997, Jette, 1997) outlines the impact of physical disease on an individual's capacity to become integrated into normal social activity. The model is based on identifying and maximizing ability. It presents conceptual links between pathology (disease), impairment (abnormality, loss of structure or function), limitations in task performance and disability in carrying out social roles and activities (Figure 1). For example, the model posits that pathology (muscle disease) causes impairment (muscle weakness) that leads to limitations (difficulty in rising from a chair) that results in disability (difficulty with maintaining mobility in day to day activities) (Figure 1).

In this study, the concepts of the Disablement Model are applied to those with a progressive dementia. Instead of physical status and disability, the concepts are related to changes in cognitive status and social ability. The current literature on cognition has not used this model but the concepts seem amenable to examining the relationship between cognition and social ability. The main pathway from disease to disability in the model is a framework for assessing the impact of the disease process on individual disability (Guralnik,

1997). The model guided this research on the relationship between cognitive limitations and social ability of individuals with a progressive dementia. The major concepts and measurements of the model are described for individuals with a progressive dementia.

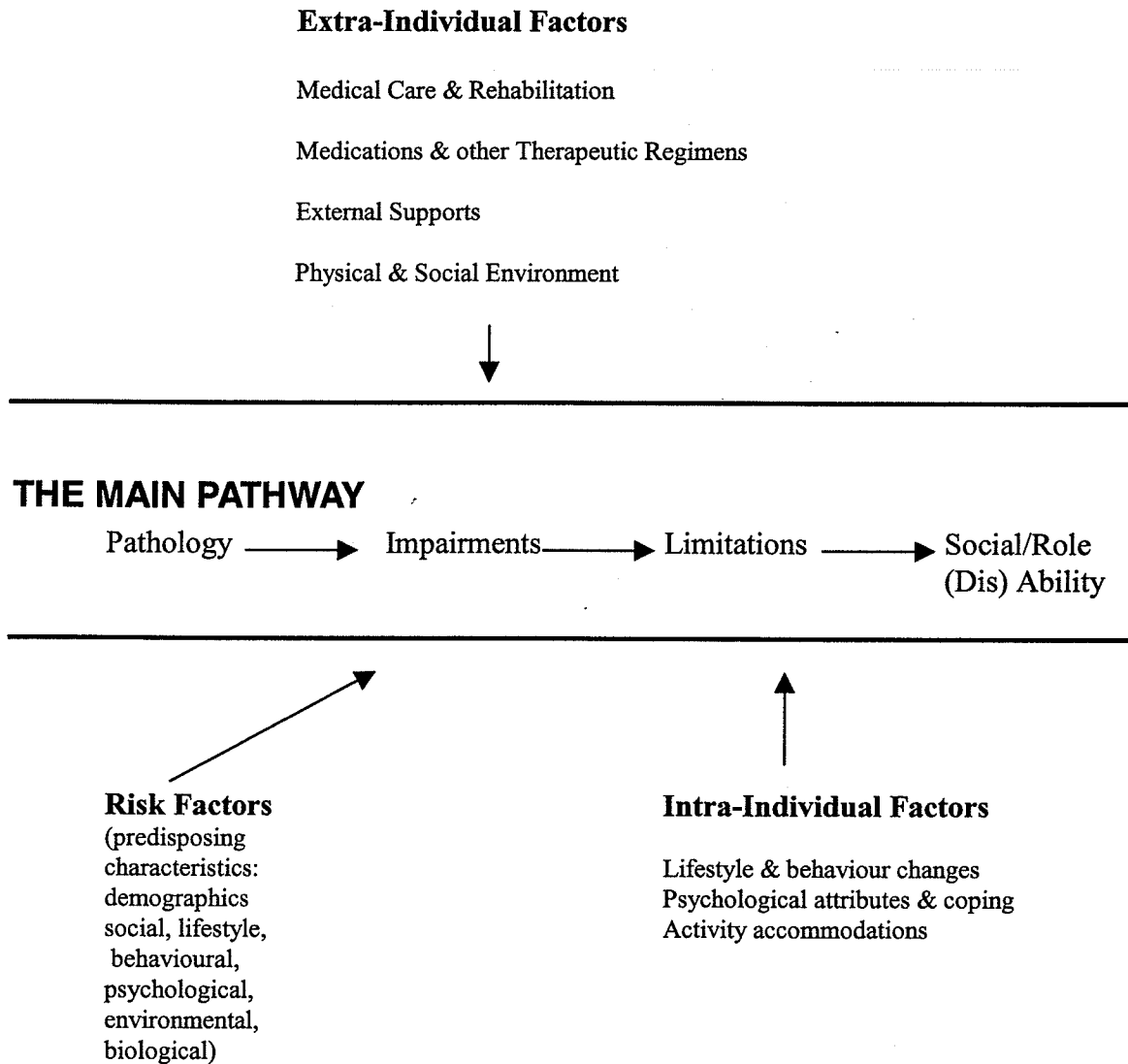
These are as follows:

*Pathology:* Pathology refers to the “interruption or interference with normal processes, and efforts of the organism to regain normal state” (Jette, 1997, p. JS30). In a progressive dementia, these interruptions are typically measured by Computer Tomography, Positron Emission Tomography and Electroencephalogram (EEG), and by other physical indicators assessed at autopsy.

*Impairment:* Defined as “dysfunctions in specific body systems.” (Guralnik, 1997, p.14).

These dysfunctions are further as “anatomical, physiological, mental or emotional abnormalities or loss” (Jette, 1997, p. JS30). For individuals with a progressive dementia the abnormality occurs in the brain. Since the brain functions to retrieve, store and encode information, a loss in mental ability occurs.

Figure 1



*Functional Limitations:* Guralnik (1997) defines limitations as deficits in basic physical and mental actions caused by the impairment. The areas of cognitive limitation that are typically examined are memory, attention, conceptualization (abstract reasoning), visual spatial skills, initiation and perseverance. Initiation refers to the capacity to start a new

activity and perseveration refers to the ability to stop an activity once it has been started. Another area of cognitive limitation less often examined is facial affect recognition, that is, the ability to discern emotion from the facial expression of others. Limitations in accurately assessing facial affect have been associated with a progressive dementia. Researchers suggest that this limitation is associated with deficits in social ability (Albert et al., 1991). Other examined areas of cognitive limitation are insight and judgement. These two areas often are assessed by clinical expertise rather than by standardized tests. *Disability/Ability:* Disabilities are the restrictions that occur in the activities of day to day life resulting from the limitations imposed by the disease process (Guralnik, 1997, Jette, 1997). Abilities refer to the remaining capacities that can compensate for these restrictions. As the disease progresses the individual with a progressive dementia experiences increasing difficulty with day to day activities, until in the latter stages these individuals are unable to toilet, bath, groom or dress themselves without the assistance of others. The abilities that continue are not routinely considered in relation to disease progression. This study was interested in evaluating the social abilities and helping abilities that continue and how they relate to the limitations that occur because of the disease process.

According to Dawson et al. (1993), social abilities are “those capacities used to interact with others and to engage in various activities using socially prescribed behaviours” (p. 44). Of further interest here is helping ability as a social ability. Helping ability is assisting another person by either the act of verbal support or the act of physical assistance (Graham & Weiner, 1991, Hutchison & Bahr, 1991).

## **1.4 Research Questions**

Examining the relationship between cognitive limitations and disability/ability for individuals with a progressive dementia has theoretical and practical implications. From a theoretical perspective, use of the Disablement Model in the cognitive domain is novel. From a practice perspective, the measurement of social ability and helping ability can expand clinical assessment (Hall & Buckwalter, 1987). Such assessment might form a basis for developing goals and interventions for care, and for enhancing quality of life in long-term care. Research that sheds light on the relationship between cognitive limitations and social ability for individuals with a progressive dementia potentially can contribute both to theoretical and practice domains.

Using the model as a guide, this research study addresses two research questions for individuals with a progressive dementia who reside in long-term care facilities:

1. What is the relationship between cognitive limitations and social ability?
2. What is the relationship between cognitive limitations and helping ability?

Subsequent chapters present the conceptual model in more detail, review the pertinent literature and describe the proposed research design.

## **CHAPTER 2**

### **Literature Review**

This research examined the relationship between the cognitive limitations imposed by a progressive dementia and the social ability and helping ability of individuals residing in long-term care facilities. This examination is guided by the concepts described in the main pathway of the Disablement Model (Jette, 1997). The main pathway of the model describes the relationship between pathology, impairment, limitations and (dis)ability (Figure 1). The model describes a number of psychosocial factors that affect the relationships among pathology, impairment, limitations and disability.

This chapter reviews the literature on the definition, measurement and interaction of the concepts of the main pathway in the model. The first two sections apply the concepts of pathology and impairment to a progressive dementia. The third section describes standard approaches to understanding and measuring cognitive limitations. The section includes a discussion of facial affect recognition or the ability to recognize the emotions of others from their facial expressions. The focus of the fourth section is the social ability of individuals with a progressive dementia. The concept of social ability is expanded to include helping behaviour. The fifth section presents literature on social ability and cognition. The final section is a summary.

#### **2.1 Pathology and a progressive dementia:**

Pathology refers to the processes that “interfere with ability of the organism to attain a normal state” (Jette, 1997, p. JS30). A progressive dementia is a

neurodegenerative disorder. Brain pathology associated with the dementia involves the development of neurofibrillary tangles in relation to abnormal protein deposits. The development of neuritic plaques, areas of granulovascular degeneration and the loss of large neurons in the frontal lobe are pathologies associated with a progressive dementia. Other abnormal changes include a decreased numbers of dendrites and neurotransmitters and a loss of synapses in the cortical area of the temporal, frontal and parietal regions of the brain.

Losses in neurotransmission are closely associated with changes in cognitive function (Wisniewski, Pirtila & Wigiel, 1998). Changes in the left hemisphere of the brain are associated with language deficits while changes in the right hemisphere are associated with spatial deficits. Frontal lobe damage is associated with decreased ability to understand and interact appropriately in social situations (Cicerone & Tanenbaum, 1997). While knowing the area of brain damage is clinically useful in anticipating the behaviour exhibited by the individual with the damage, the link between the damaged area and the disabilities or remaining abilities of the individual is not precise (Kolanowski, 1996, Milberg, 1996).

The extent of brain pathology and the type of pathological change can be determined only at post mortem for AD (a progressive dementia) (Blessed, Tomlinson & Roth 1968). Prior to death, other procedures and techniques of assessment can be used. Positive Emission Tomography (PET) is a technique that has been used to identify the specific areas of the brain that is affected in a progressive dementia associated with AD. Due to cost and availability, this technology is not routinely available for individuals



presenting with AD. Albert et al. (1991) suggested that the rate of deterioration of the brain affects the degree of deficit, that is, an individual with sudden brain damage (e.g. stroke) will experience greater cognitive deficit compared with someone whose brain damage had been insidious. Current knowledge of the disease process, cognitive deficits and the expression of behaviour is inexact and requires further attention (Bayles, Kasniak & Tomoeda, 1987).

## **2.2 Impairment and a progressive dementia**

Impairments are dysfunctions that occur at the organ level. In a progressive dementia, the impairment is reflected in the brain's ability to take in, store, retrieve and interpret sensory information (Foremen, Fletcher, Mein, Simon & Faculty, 1997). The amount of information that can be assimilated and interpreted from the environment is altered and diminished for individuals with a progressive dementia. The impact of impairment is usually framed in terms of the cognitive limitations experienced by individuals with a progressive dementia.

## **2.3 Limitations and a progressive dementia**

Limitations are restrictions in basic physical and mental actions, for example, to walk, to reach and to produce intelligible speech. This research focuses on the cognitive limitations that occur in a progressive dementia. Cognitive limitations are defined by changes in the individual's memory, ability to attend to information and conceptualize, visuospatial capacity, and the ability to begin (initiation), and stop a task (perseveration). Several tools exist to detect cognitive limitations. One widely used standard instrument is the Dementia Rating Scale (DRS) (Mattis, 1976). This tool measures ability in discrete

domains of cognition such as memory and visual spatial ability (Vitiolano, Bran, Albert, Russo & Prinz, 1984) as well as providing a global measure of cognitive deficit (i.e., a cumulative score of deficits across domains).

Although measured less often as a cognitive limitation, the ability to recognize facial affect was examined in this research because of the suggested relationship between facial affect recognition and social ability (Albert et al., 1991). Facial affect recognition has been measured using an item created by Dawson et al., (1993) where a series of photographs depicting emotion are displayed and the individual is asked to identify the emotions.

The definitions and measurements of memory, attention, conceptualization, visual spatial ability, initiation, perseveration, and facial affect recognition are presented in the next sections.

### **2.3.1 Memory**

The mental processes involved in assimilating information including acquisition, retention and retrieval are aided by the capacity of the individual's memory. Memory is the major function that declines in individuals with a progressive dementia. A variety of types of memory have been studied, including memory for verbal, auditory, and visual spatial information. The literature commonly refers to the memory as having two components. The first is the physical structure (hardware) and the second is the processes (software) that facilitates the movement of information within the structure. The length of time that information has been stored in the memory often distinguishes different types of memory. Memory is usually described as primary or short term, secondary or long-

term and tertiary or remote memory. Primary memory is the temporary storage area for information needed in the performance of tasks (Nebes, 1992). Primary memory is thought to be the central executive of the flow of information between the memory systems (Conway, 1997).

Secondary memory is the permanent storage of unlimited amount of information. It has been suggested that the major memory deficit of individuals with AD is in the storage and retrieval of information in the secondary memory (Nebes, 1992). Information retrieved from secondary memory is stored in the primary memory to use when a current problem requires this knowledge.

Changes in memory capacity for individuals with a progressive dementia manifest in several ways. Individuals with a progressive dementia may no longer have the capability to cook because they forget to turn off the stove or to go out on their own because familiar areas lose their familiarity. They are unable to execute solutions to simple problems due to their increasing difficulty with memory. Clinically determining the extent of the deficits entails some standardized approaches; for example, by asking the individual to recall specific information such as the specific date and current location or to recall words or sentences previously provided. The DRS (Mattis, 1988) taps short term memory by asking a set of questions about the day, date, month and year, as well as questions about current political leaders and the individual's current physical location. Memory in the DRS is also measured by asking the individual to read a sentence then recall the sentence some time latter. The individual is also asked to recognize a set of words that they were previously asked to memorize. The DRS attempts to distinguish

differences between verbal recall and visual recall. Another item asks the individual to recognize pictures of designs that had been previously presented.

### **2.3.2 Attention**

“Attention is the mechanism by which a subject allocates a limited processing capacity to certain information or to certain mental operations” (Nebes 1992, p.378). Tests directed at measuring attention attempt to detect deficits in the individual’s ability to maintain concentration and to resist distraction (Nebes, 1992). Individuals with a progressive dementia have great difficulty dividing their attention between different sources of information (Nebes, 1992). Inefficiencies in the ability to suppress irrelevant information from coming into primary memory are typical for individuals with AD (Nebes, 1992, Hess, 1994). The DRS has 6 items to test attention. One item is the commonly used digit span method, that is, the individual is asked to repeat a list of numbers backward (up to 4 digits). The second item asks the individual to follow two consecutive commands, that is, to open the mouth and close the eyes. If the individual is unable to do this task, a simpler task is requested. This task asks the individual to watch and imitate the examiner’s actions. Attention is also measured by requesting the individual to identify all the A’s in a symmetrically patterned display of random letters and to identify all the A’s in a nonsymmetrical pattern of random letters.

### **2.3.3 Conceptualization Abilities**

Conceptualization is the ability to identify patterns of similarities and/or differences between objects (Mattis, 1988). Changes in this cognitive ability is measured by determining if there is a deficit in recognizing and categorizing items (Nebes, 1992).

Individuals with this limitation are not able to recognize that an orange and an apple are both fruit. The DRS has several items that measure this limitation. For example, an item in the DRS asks the individual to recognize similarities and differences in a set of designs and in sets of words (apple and orange).

#### **2.3.4 Visual Spatial Abilities**

Visual spatial abilities include visual perception and constructional praxis (the ability to manipulate objects in space). It has been suggested that many of the problems that individuals with a progressive dementia experience with using items in their environment is due to changes in their visual spatial abilities. They no longer know how to use a fork or knife or flush a toilet (Nebes, 1992). As with other limitations, individuals with a progressive dementia demonstrate considerable variation in terms of visual spatial abilities (Nebes, 1992). Visual spatial abilities are usually measured by requesting the individual to replicate a geometrical design. The DRS has items that range from complex to simple and the individual with the dementia is requested to replicate them.

#### **2.3.5 Initiation and Perseveration**

Difficulty initiating and stopping activity is a cognitive limitation associated with a progressive dementia. The DRS measures the extent of this limitation by asking the individual to begin, switch and end specific activities. Both motor and verbal motor skills are assessed. Motor skills are tested by asking the person to imitate the examiner's body motions (in one example, the examiner has one hand palm up and the other palm down and switches the hand positions). Visual motor skills are examined by requesting

the individual to copy a design. Verbal initiation and perseveration is tested by requesting the individual to list objects that could be bought in a supermarket (within a time limit). If unable to perform this task, the individual is asked to repeat like sounds in sequence such as bee, key and gee.

### **2.3.6 Facial Affect Recognition**

Facial affect recognition has been examined in several studies as a separate cognitive ability (Brosigle, Kurucz, Plahavinsak, Sprotte & Haveliwala, 1983, Bowers, Bauer, Coslett, & Heilman, 1985, Etcoff, 1984). While evidence suggests a loss of facial affect recognition in individuals with dementia (Brosigle, Kurucz et al., 1983), research is not conclusive. Albert et al. (1991) concluded that limitations in facial affect recognition were actually losses in the ability of individuals with AD to communicate their understanding of facial affect.

In the Abilites Assessment Instrument (AAI) developed by Dawson et al. (1993), the ability to recognize facial affect involves first showing the individual three pictures depicting the facial emotions of sadness, happiness and anger. Each picture is shown one at a time and each person is asked if the face is happy, sad or angry. A 'yes' or 'no' result is solicited. In a study using this instrument, 112 men with a diagnosis of different types of dementia were assessed for their retained abilities (Wells et al., 2000). The results showed that 57% of 112 cognitively impaired men attained a high level of ability for facial affect recognition (greater than 75% in score), 12% attained a moderate level of ability (between 50 and 75%), and 31% achieved a low level (a score of less than 50%). The average score for the 112 men in facial affect recognition item was 50%.

Hoffman, Platt, Barry and Hamill (1985) conducted a study to determine how individuals with dementia responded to pleasant and unpleasant behaviours of others. Fifty-four individuals with dementia were observed for their response toward the relaxed, smiling face of the interviewer (pleasant) and the frowning and angry expression (unpleasant) of the interviewer. Positive behaviour was recorded when the individual maintained eye contact with the interviewer or was smiling or had relaxed facial muscles. Negative behaviour was recorded when the individual avoided the interviewer. All of the individuals responded positively to pleasant behaviours of the interviewer and all of them negatively to unpleasant behaviours.

#### **2.4 Disability/Ability**

Disability is defined as difficulty in performing “socially defined roles within a sociocultural and physical environment” (Jette, 1997, p. JS30). For this research, the focus was on abilities rather than disabilities in the social domain. Ability in long-term care is most commonly defined and measured as the degree to which a person carries out the tasks of bathing, toileting, dressing, grooming, eating and transferring (Katz et al., 1963). Heacock, Walton, Beck and Mercer (1991) indicate that some abilities are embedded in “well-preserved memory”, that is, the repetition of these tasks during a lifetime results in retention or remnants of these abilities in individuals with a progressive dementia. Anecdotal comments from the literature suggest that social abilities, like everyday tasks, are also embedded in well preserved memory. ‘Some people with AD can maintain their social graces and on superficial examination can appear to be cognitively normal’ (Luxenburg, Lawrence & Feigenbaum, 1986, p. 796).

Dawson et al. (1986) and Baum, Edwards, and Morrow-Howell (1993) also suggest that social abilities in individuals with a progressive dementia are maintained in the face of cognitive losses.

#### **2.4.1 Social Ability and Helping Ability**

Social abilities are those “capacities used to interact with others and to engage in various activities using socially prescribed behaviours” (Dawson et al., 1993, p.44).

Baum et al. (1993) defines socialization as the abilities of a person to engage with others in conversation and during social activities. Kelley (1997) stresses the significance of the ability to communicate and send and receive verbal and nonverbal messages in order for a social interaction to occur.

Researchers who examine the social abilities of individuals with a progressive dementia have identified several behaviours as important social abilities. One of these abilities is to give and receive attention (Dawson et al., 1993, Kitwood, 1995, Sabat & Collins, 1999). Included in these abilities is the ability to initiate social interaction with familiar others (Baum et al., 1993, Mayhew, Acton, Yauk & Hopkins, 2001, Sabat & Collins, 1999). Other behaviours identified by researchers include: engaging and participating in conversation, engaging in topics of interest, recognizing social stimulus and responding normally to social situations. Behaviours also include the ability to appreciate humor, to show enjoyment and to be helpful to others (Dawson et al., 1993, Baum et al., 1993, Sabat & Collins, 1999, Kitwood, 1995).

Sabat and Collins (1999) and Kitwood (1995) both suggested that helpfulness including showing affectionate warmth for others are attributes of social ability. The



ability to feel sympathetic and act on those feelings is described as an innate human characteristic (Graham & Weiner, 1991). Hutchison and Bahr (1991) interviewed cognitively intact residents of a nursing home and asked about their perception of socially productive acts. The residents reported the act of caring as a behaviour that made them feel productive. Specifically, properties of caring were identified as protecting, supporting, confirming, and transcending. Protecting, for example, meant watching someone to make sure he/she came back to the room. Supporting was described as comforting and providing solace to those who were upset. Confirming meant being respectful to others in spite of their difficult behaviours and transcending meant engaging in prayer with someone. A study of 16 cognitively impaired male residents of a Veterans Nursing Home found that the most important aspect of self-perceived quality of life was the opportunity to help others and to participate in activities (Oleson et al., 1998).

#### **2.4.2 Measurement of Social Ability and Helping Ability**

Two standardized instruments specifically measure the social ability of individuals with a progressive dementia. One is an instrument developed by the by Baum et al. (1993) and the other one was developed by Dawson et al. (1993).

Baum et al.'s (1993) instrument is called the Functional Behavioural Profile. The Functional Behavioural Profile measures productive behaviour. Productive behaviours include the ability to perform tasks, solve problems, and to interact with others (socialization). Socialization includes the ability to show enjoyment and participate in activity, to initiate conversation with family, to identify familiar people, and to express oneself appropriately. Measurement relies on the retrospective information from a proxy,

usually the family caregiver. Family members are asked to rate the extent in which a behaviour occurs. This measurement approach facilitates insight into social behaviours that need to be recognized and encouraged in those with a progressive dementia. However, the family caregiver could miss behaviour that indicates the social ability of the individual with a progressive dementia. The literature suggests that measurement of behaviour of the individual with a progressive dementia requires observation of the subtle behaviours that are required to complete a task (Tappen, 1994, Beck et al., 1991).

Dawson et al.'s (1993) instrument, the Abilities Assessment Inventory (AAI), encourages the observation of subtle behaviours by providing the context in which the social behaviour can occur. The social abilities are described in the Abilities Assessment Inventory (AAI) (Dawson et al., 1993). The AAI has 4 subscales including self-care, interaction, interpretive abilities and social ability. The Self-Care Abilities Subscale measures basic everyday activities such as bathing, grooming and toileting. The Interaction Abilities Subscale focuses on language ability and the Interpretive Abilities Subscale focuses on abilities such as recognizing time and identifying objects by touch. It also has items that determine if the individual recognizes him/herself in the mirror and familiar others, and if he/she can recognize the emotions of others by their facial expression (facial affect recognition). The Social Abilities Subscale (SAS) consists of 3 categories of abilities including, the ability to give and receive attention, the ability to engage and participate in conversation and the ability to appreciate humor.

This research relied on Dawson et al.'s (1993) Social Abilities Subscale (SAS) of the (AAI). This tool was developed to provide nurses working in long term care facilities

a means of measuring social ability of individuals with dementia. Properties of the tool have been reported (Dawson et al., 1998, Rivera, 1999).

Dawson et al.'s (1993) measurement of social ability entails a systematic recording of the individual's response to social cues. For example, the SAS rates the individual's response to "Hello", "Good morning". The highest scored response is a verbal reply, followed by nonverbal responses of a smile, then eye contact, then muttering and finally by no response. The score for the items ranges from 3-0 or 4-0 depending on the item and the highest score indicates the greatest social abilities.

As well as addressing the social abilities using the SAS, this research addressed helping ability as a social ability. There were no measures of helping ability in the literature for individuals with a progressive dementia therefore two helping ability items were developed for this research and the items follow the same ordinal format of Dawson et al. (1993). These helping items are the verbal-helping item and the physical-helping item. The goal of the items is to provide context that solicits the helping behaviour of the resident. The helping ability items require the individual to respond to the verbal and nonverbal cues of the interviewer. More specifically, for the verbal-helping ability item the individuals with a progressive dementia are scored according to their response to 2 different statements. Helping statement 1 is "I am sad" and helping statement 2 is "I am sad because a cat I had for 20 years died last night." Highest score is allocated to a sympathetic verbal response entailing a description of a loss that occurred to the individual with a progressive dementia or a request for more details about the loss experienced by the person making the statements. Less complex verbal responses

followed by a series of nonverbal responses and finally no response have progressively lower scores. The physical-helping item involved observing if the individual responds to someone dropping an item. Helping ability is demonstrated if the individual picks the item up or informs the person who dropped the item that it was dropped. If they do not respond to the dropped item they do not demonstrate helping ability (yes=helping, no=not helping).

## **2.5 Social Ability of Individuals with a progressive dementia**

Literature on social ability and a progressive dementia is presented in 5 sections. The first section reviews empirical studies of the relationship between cognitive limitations and social ability. The second section presents literature on the abilities of individuals with dementia to attend to the social context. The third section describes studies that examine individuals with AD and their ability to convey a message through verbal communication. The fourth section deals with the social ability associated with being able to appreciate humor. The last section presents studies on helping behaviour of individuals with a progressive dementia.

### **2.5.1 Cognitive Limitations and Social Ability**

Little research has been carried out on the relationship between cognitive limitations and social ability (Wells & Dawson, 2000). Exceptions are the work of Baum et al. (1993), Dawson et al. (1998), Wells and Dawson (2000) and Rivera (1998).

Baum et al. (1993) conducted a study to identify and measure the productive behaviours of individuals with AD at different stages of dementia. A convenience sample of 106 community dwelling individuals with dementia was selected. Productive behaviour

was measured using the Functional Behaviour Profile. Using this instrument, family members rated the extent to which their relatives had retained certain behaviours. Individuals with a progressive dementia were assessed by neuropsychologists and psychiatrists with the CDR (Clinical Dementia Rating Scale) The CDR was used to identify the levels of dementia. The levels of dementia it identifies are questionable, mild, moderate or severe. The CDR is a reliable and valid tool for determining the level of dementia in the domains of memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care (Baum et al., 1993).

Baum et al. (1993) reported a direct relationship between cognitive limitations and socialization behaviour. Specifically, a significant correlation of .77 between problem solving (as a measure of cognitive limitations) and socialization was reported. The task of problem solving included three step commands, learning complex tasks, knowing the day of the week, making decisions, and problem solving with assistance and without. Socialization was measured in relation to the individual's engagement with others in conversation and social activities. Socialization activities included: shows enjoyment in activities, socializes when others initiate, participates in activities, initiates conversation with family, expresses self appropriately, performs activity without frustration, makes decisions when given choices and continues activities when frustrated. A significant correlation of .66 was found between a measure of global cognition limitations (the Short Portable Mental Status Exam) and socialization.

Baum et al. (1993) also reported on the relationship between the stages of dementia and the types of retained abilities. There was a significant decline in problem

solving ability between the questionable stage and the mild stage of dementia while socialization had a significant decline between the moderate and severe stage of dementia.

Baum et al.'s (1993) study demonstrated that in spite of the dementing process and the cognitive limitations associated with this process, family members of individual's with AD can identify many behaviours that suggest that social interaction abilities remain intact until later in the disease course. The positive significant relationship between cognitive decline and socialization is likely related to declines in social interaction that do not occur until the later stages of dementia.

An evaluation study of the psychometric properties of the Abilities Assessment Inventory (AAI) and the Social Ability Subscale (SAS ) also shed light on the relationship between cognitive limitations and social ability of individuals with dementia (Dawson et al., 1998). A sample of 112 cognitively impaired elderly men and 60 nonimpaired men who resided in an extended-care department of the university hospital were administered the AAI. The 112 men had a variety of types of dementia, including the AD type, multi-infarct and Korsakoff's dementia. The mean age was 75 years and the average length of stay was 313 days. The method of detecting dementia relied on a standardized workload classification system and the agreement of the nursing unit director or primary nurse on the classification.

In this study, there was a significant difference between the cognitively intact group and the group with dementia in relation to their social abilities with the cognitively intact group exhibiting higher levels of social ability. This seems to indicate a decline in

social abilities with cognitive limitations, however the level of cognitive ability that connects with the decline of social ability is not explained in this study nor was the type of limitation indicated.

In another report of the same study Wells and Dawson (2000) provided further evidence of social ability in the later stages of the dementing process. The social ability of the same 112 cognitively impaired men, 83% of whom had moderate to late stage dementia as measured by the FAST was reported. Scores in the AAI subscales were used to divide the abilities according to high level of ability, moderate level of ability and low level of ability in each category (i.e., self care, interactional ability, interpretive ability and social ability). High level of ability corresponded to having a score of greater than 75% on the subscale, moderate level to a score of 50-75% and low level to a score of <50%. Examining social ability scores and comparing them to items from the interpretive subscale and the interactional subscale that measure typical cognitive limitations, provided information on the relationship between cognitive limitations and social ability.

Wells and Dawson's (2000) study found that 60% of the men demonstrated high social ability, 26% attained a moderate level of ability and 14% retained a low level. The abilities were further broken down into SAS items. For the attention and humor item 62% of the 112 men had a score greater than 75%, 26% scored at a moderate level and 12 % scored at a low level. In the conversation item, 68% attained a high level of ability, 14% attained a moderate level of ability, and 18 % attained a low level of ability. Across AAI subscales, it seemed that the men showed the highest level of ability in the SAS.

The mean percentage score in social abilities was 73.9 % compared with 58.6 % and 52.3% for interactional abilities and interpretive abilities respectively.

Riveria (1998) examined the psychometric properties of the SAS on a group of 30 elderly women who were cognitively impaired and a group of 30 women who were not impaired. The subjects in this study were chosen from one of 6 medical surgical/ medical units at a university hospital. The subjects were considered medically stable. The Mini Mental State Exam (MMSE) was used to describe the cognition of the women in the study. The MMSE is a global measure of cognitive impairment that is commonly used to screen for dementia. The maximum score on the MMSE is 30. The cut-off for cognitive impairment in this study is 23. A score of 24 or more indicates the person is not cognitively impaired. The SAS has a scale range of 1-29.

Rivera's study (1998) indicated that the cognitively impaired group had severe cognitive impairment, with an average MMSE of 7/30 and a range of 0-16. The average score on the SAS attained by the cognitively impaired group was 22 with a standard deviation of 3.9. In contrast, the average MMSE score on the noncognitively impaired group was 29 with a range from 25-30 and the average SAS score was 28. There was a significance difference in SAS scores between groups. This suggested a direct relationship between cognition and social ability. However, there was considerable variation in social abilities within the cognitively impaired group (range 12-27).

Overall, the few studies that examine cognitive limitations and social ability suggest a direct association between social ability and cognitive limitation. The studies also suggest that some individuals with AD retain their social abilities. Further



examination of the association between the cognitive limitations and the social abilities that remain intact are provided in literature that examine specific attributes of social ability. These specific attributes include the ability of the individual with a progressive dementia to attend to social context, the ability to communicate a message, the ability to engage in humorous activity with another and helping abilities.

### **2.5.2 Attending to Social Context**

The ability to attend to situations is revealed when individuals initiate social interaction with familiar individuals, and respond to a social situation by engaging in verbal or nonverbal interactions with the other person (Sabat & Collins, 1999).

In a case study, Sabat and Collins (1999) observed the social abilities of a woman with dementia who attended an adult day centre. They described the woman's cognitive limitations as including deficits in the ability to follow verbal instructions, to attend to one topic, to stay on task, to complete a sentence, to 'word find' and to organize motor movements required to dress or eat. The woman had been assessed as having a moderate to severe level of dementia. She indicated attention to social situations by initiating social contact through her own facial expression, vocal tone and verbal utterances. For example, the woman was observed listening to another person who tended to talk and repeat statements. The woman was observed nodding her head and commenting, "Oh my". Usually, she only responded to others when social contact was initiated but on one occasion she was observed initiating social contact. The woman initiated contact by shaking hands and winking and smiling when eye contact occurred.

Mayhew et al. (2001) described the ability of 5 individuals with severe

Alzheimer's type Dementia to relay information about themselves and their lives using videotaped analysis of their communication. The Mini Mental Status Exam (MMSE) and the Reisberg Functional Assessment Scale rated severity of dementia. The 5 individuals had an average MMSE of 4.6/30 and were at the beginning of stage 7 (severe dementia). The videotaped stories were analyzed for content and meaning. The analysis indicated that these individuals understood the expectations of the study. The individuals relayed stories about their lives and their emotional responses to life's circumstances.

Using 6 different anecdotal descriptions of the social interactions of individuals with AD Buckwalter et al. (1995) illustrated the ability of attending to social context. In each of the descriptions, the family caregiver was surprised by their relative's ability to suddenly respond appropriately to a social situation. For example, a man in the latter stages of AD was often calmed by his wife with pictures of the "old days". One day when his wife became frustrated and began to cry, he came over to her, placed his arm around her, and retrieved the album of old photographs. To his wife's surprise he stated, "maybe this will make you feel better." Another anecdote suggested that people even with severe dementia have the ability to attend to the context of a social interaction. For example, a social worker and the daughter of a severely demented woman were discussing the difficulties the daughter had coping with some of her mother's repetitious behaviour. The mother overheard the daughter's and stated "if she had not been repetitious, then the daughter would not have been born."

In general, individuals with AD demonstrate the ability to attend to social context by engaging in nonverbal and verbal interactions that 'fit' with the social context. The

literature tends to rely on the observational case study research or anecdotal reports.

Empirical research in this area is lacking.

### **2.5.3 Communication: Sending a Message**

The ability to communicate is essential to the social human nature. Knuf (2000) applied aspects of communication theory to the issues impacting communication of those with dementia. He defines the process of communication as including the “encoding of a message into spoken words, which are then decoded by the communicative partner” (Knuf, 2000, p. 486). The ability to communicate using verbal messages is an aspect of the social abilities that tends to decline for individuals with AD. Knuf (2000) argues that the process of communication between individuals with AD and others is no different than with any 2 individuals. Communication occurs within the social context and he states that communication competence occurs in the interpersonal framework of care recipient and caregiver, in which mutual understanding is negotiated and achieved” (Knuf, 2000, p. 490). A few studies illustrate the specific trait of relaying a message through verbal and nonverbal means.

In the observational study by Sabat and Collins (1999) a woman with AD was described as having “creative linguistic capabilities”. The woman used paralanguage to convey information. For example, when trying to explain the meaning of the word muggy to another person in the day care centre, the woman searched for words, presented a facial expression and then said “blech”. Another example from the same woman was her description of one of the volunteers who worked at the day care centre. She stated the woman “was not persy” and at the same time exhibited a face with nose turned up and

pursed. When asked if she meant the volunteer “was not prissy”, the woman replied “yes”.

There are 3 studies that systematically identify the potential that exists for individuals with AD to send a variety of responses to a social interaction (Acton, Mayhew, Hopkin & Yuak, 1999, Mayhew, Acton, Yauk & Hopkins, 2001, William & Tappen, 1999). The purpose of the study by William and Tappen (1999) was to determine if it was possible for an Advanced Practice Nurse to develop a therapeutic relationship with an individual with AD. In this study, conversations between individuals with moderate to late stage of dementia and Advanced Practice Nurses were recorded and analyzed. The purposive sample of 42 nursing home residents with AD consisted mainly of women with a mean Mini Mental State Exam score of 9.8. Transcripts were made of conversations between the residents and the Advance Practice Nurse 2-3 times over a 16 week period. Narrative analysis was used to analyze the interactions.

Findings indicated that these residents were able to communicate resistance, anxiety, low self-esteem, affection and desire for the relationship to continue. For example, resistance was communicated in this resident’s response to a staff nurse, “This is not a conversation. What we’re having. It is nothing” (William & Tappen, 1999, p. 32). Two residents illustrated low self-esteem, one stated “I talk to you and I am afraid that you will say that she is crazy. She is crazy, me, me” (p. 32), another stated, “I am nothing. I have become myself, that’s all. I am restricted to myself” (p. 32). An incident that illustrated resident anxiety was evident in this example when the nurse observed the resident searching his pockets. The nurse said, “You have nothing in your pocket”. The

resident replied, "That's right, absolutely nothing. So I got scared, I don't know" (p. 32). Affection in relationships was also demonstrated when a resident indicated that he/she liked the nurse after the nurse pointed to the residents name on a greeting card, "Who is this?" The resident responded by saying, "Someone who likes you" (p. 32).

A second study using an ethnographic naturalistic design explored the content and meaning of communication received between individuals with AD and interviewers (Acton et al. 1999). This study asked whether or not individuals with AD could transmit messages. Twenty interviews were selected at random from a larger study and analyzed for their content. The interviewers asked open-ended questions to obtain information on stress, their sources of support, and identified strengths. The themes generated from the transcripts illustrated the communication abilities of individuals with AD. The themes included concerns about burdening others with their illness, positive and negative feelings about family, awareness of cognitive and physical limitations. Other themes included expressing positive feelings about the past, feelings of spirituality, concern about the future, and feelings of loss. The efforts made to ensure trustworthiness of the data were described as part of the research process. Inter-rater reliability was .86. Intra-rater reliability was established at .89.

In the third study individuals with severe dementia were able to respond through extra sounds and nonverbal behaviour (Mayhew et al., 2001). Analysis of these individual's stories required identifying key words. Two separate investigators agreed that the 5 individuals expressed a wide range of messages. Some of these included: awareness of cognitive decline, awareness of self and indicators of well-being, ability to

express a range of emotions, assertion of desire or will, and social sensitivity.

A study by Moxley et al. (1998) demonstrated the ability of individuals with AD to answer specific questions on a Quality of Life questionnaire. It has sometimes been assumed that individuals with AD are limited in their ability to express an opinion about the quality of their lives in a nursing home. The ability to answer quality of life questions was examined for individuals with AD (Moxley et al., 1998). A convenience sample of 308 residents were interviewed within 2 weeks of admission to a nursing home in England. Quality of life was measured using an adapted Lancashire Quality of Life Profile (LQOLP). The scale includes items on leisure, family relations, living situation and health. Items related to work, education and salary were omitted and items related to the food in the home and occupation opportunities were added. The residents in the study were asked to rate the extent in which they disagreed or agreed with statements about the above quality of life issues. The MMSE exam was used to assess the level of cognitive impairment and the different domains in the MMSE were analyzed for their relationship to the interviewability of residents.

Interviewability was defined as being able to provide answers in response to the questions in the LQOLP. The interviewer had to be confident that the subject was understanding and answering the questions appropriately (Moxley et al., 1998, p.A778). Findings indicated that 77.5% of people with a score of 10/30 and above were considered interviewable. Each domain of the MMSE was examined to determine the significance of the discreet measures of cognition to the interviewability of the client. Visual construction, registration and recall were the domains that had no relationship to the

interviewability of the individuals with AD. This study suggests that the ability to communicate preferences is maintained even in those with a high degree of cognitive limitations. The assumptions that individuals with cognitive limitations are incapable of expressing preferences is questionable.

The ability to communicate in the face of moderate levels of dementia was illustrated in a study of 34 community dwelling individual with a diagnosis of mild to moderate AD (Vitaliano, Breen, Albert, Russo & Prinz, 1984). The purpose was to examine the relationship between cognitive performance and abilities in activities of daily living (feeding, toileting, dressing), managing personal belongings, recreation (reading, writing and doing hobbies) and communication (talking, and listening). Cognitive performance was described by certain items in the DRS (Mattis, 1988) and the MMSE that measured orientation, recognition memory, recall, attention and calculation. The instrument used to gather information on communication was the Record of Independent Living developed by Weintraub et al. (1982) in Vitaliano et al. (1984). This instrument was used because it includes a wider range of activities than most instruments for evaluation of mildly and moderately impaired individuals with AD. In this study findings indicated no significant relationship between cognitive performance and communication. That is despite changes in cognitive performance there was no difference in the ability of the individuals with AD to talk and listen effectively.

Overall, these studies suggest that individuals with AD continue to communicate meaning through both verbal and nonverbal expression. The need to understand context and interpret the emotional meaning of the message is clear in the examples provided. A

major reliance on interpreting verbal information within an interaction with a person with AD decreased attention to other aspects of social ability that may continue to exist. The studies illustrate that individuals with AD are capable of communicating their feelings and opinions.

#### **2.5.4 Humour**

Responding to humorous situations and making a joke has been observed in individuals with moderate and severe cognitive limitations (Acton et al., 1999, Dawson et al., 1993, Kitwood, 1995, Sabat & Collins, 1999, Wells & Dawson, 2000). This literature suggests that the ability to recognize and make light of situations remains in individuals with dementia.

In a single case study, Sabat and Collins (1999) observed a woman with AD laughing at her own word finding difficulties and solutions. Similarly, the study by Acton et al. (1999) illustrated that individuals with AD do engage in humorous social interaction. Laughter was recorded in 100% of the individuals with dementia and 60% of individuals with dementia showed their ability to use humour in social interactions.

In a study that examined the ability of 30 men to respond to visual and verbal humour, Dawson et al. (1993) found that 64% of the men laughed or smiled at the 'punch line' and 60% of the men laughed at the cartoon. Three verbal jokes and four cartoons had been selected on the basis of gender and cohort preference. Humour was measured by whether the individual laughed, smiled, changed facial expression, had an unexpected reaction or showed no response. Unexpectedly it was found that several of the individuals with AD continued to tell jokes of their own after the 'study' joke was



completed.

Kitwood (1995) collected retrospective observational information from 10 formal caregivers (working in long term care facilities) on their perceptions of the positive behaviours of 49 residents (40 woman, 9 men) with moderate to severe dementia. In an open ended question, Kitwood asked the formal caregiver, if they had observed any other positive increased change. Caregivers identified humour appreciation and laughing as a positive behaviour that increased in some of the residents over time.

Overall, the ability of individuals with AD to enjoy the company of others by engaging in humorous activities was illustrated in these case studies and findings.

#### **2.5.5 Helping Ability**

As presented earlier, several studies suggest that individuals with AD retain social abilities even in the face of high levels of cognitive limitations. Furthermore, Acton et al. (1999) reported that “meaning in life” was a theme generated through interviews with individuals with AD who were asked to talk about things that mattered to them. Helping and caring abilities of individuals were identified in this study as providing meaning to the individuals with AD. Helping and caring ability of individuals with AD has been demonstrated in a few studies. The type of helping ability examined by studies varies and includes expressing warmth and pleasure when interacting with others, providing support to others by listening and providing physical help and the willingness to help by participating in a research study.

Three studies described the ability of individuals with AD to show warmth (Kitwood, 1995, Mayhew et al., 2001, Sabat & Collins, 1999). A single case study

described by Sabat and Collins (1999) illustrated that a woman with a moderate level of AD type dementia expressed pleasure and warmth with greetings and appreciation for the thoughtful gestures of others. She also displayed supportive behaviour by listening to a woman who spoke nonsensically. In a study by Kitwood (1995), caregivers reported that residents with a progressive dementia displayed increased warmth and affection as their dementia progressed. In this study 10 formal caregivers of individuals with dementia completed a questionnaire on their perceptions of positive changes that had occurred over the course of caring for 49 individuals with moderate to severe dementia. Kitwood (1995) reports that the caregivers found that 84% of the 49 residents displayed increased warmth and affection. Caregivers also indicated in open-ended questions that they felt that individuals with AD expressed a concern for others, sociability, and capacity for friendship.

The ability to communicate warmth and caring was identified in a study of 5 severely demented individuals who were asked to tell a story about their lives (Mayhew et al., 2001). In this study, an example was cited that described a woman who expressed affection for her granddaughter. The description included both the nonverbal behaviour (voice tone, smile and laugh) and her words. Another theme generated from the stories of these individuals was the interest and willingness to help. An excerpt used to illustrate this ability was an individual with severe AD stating "I sure would like to help you... I'd like to help you it's just not back in my head" (Mayhew et al., 2001, p. 108).

The ability to help others is illustrated in an observation study by Sandman, Morberg and Adolfsson (1988). In this study the social interactions among 5 individuals

with AD who resided in a psychogeriatric unit at a mental hospital were observed using a videotape. The purpose of the study was to determine if staff presence affected the social interaction and meal behavior of individuals with AD during their meal period. The observation took place over a 3-week period during all meal periods (the total time of observation was 1.5 - 2 hours per day). There were four different situations in which the 5 individuals with AD were observed for their social interaction and meal behaviour. The first situation was an acclimatizing process and the staff assisted those who looked like they needed or requested help with their meal. The second situation observed their interaction when the individuals with AD were left alone while eating. In the third situation, 2 nurses were dressed in civil clothes and were available during the mealtime to assist the individuals. In the last situation the nurses were still present but they were wearing uniforms rather than civil clothes. It was found that when the group of 5 individuals with AD was left alone that 2 individuals who were the least cognitively impaired of the group assisted the others with their meals. One of the more cognitively intact of the 5 individuals with AD actually fed one of the others who had more functional difficulty. The conversation and behaviour during the time that these 5 individuals were alone indicated that they became more tolerant of difficulties experienced by each other during mealtime.

Despite the importance of helping ability as a human characteristic, little systematic study has been carried out on the helping abilities of individuals with a progressive dementia. Identifying and documenting this human characteristic in individuals with a progressive dementia facilitates a greater understanding of how the

disease process does or does not express itself. Studies done to date, while instructive, have relied on retrospective data from formal caregivers (Kitwood, 1995), or have very small sample sizes (Mayhew et al. 2001, Sabat & Collins, 1999). This research aimed to explore helping behaviour of individuals with AD using a systematic procedure.

## **2.6 Summary**

The purpose of this research was to examine the relationship between cognitive limitations and social ability. The Disablement Model provided a framework for considering the relationship between cognitive limitations and social ability of individuals with a progressive dementia. The main pathway of the model describes a relationship between pathology, impairment, limitations and disability. The application of these concepts to progressive dementia is novel. Common methods of defining and measuring pathology and impairment for progressive dementia do not provide sufficient information to the clinician on either the expected degree of cognitive limitations or the extent of disability.

Few studies have examined the relationship between cognitive limitations and social ability. This literature review has defined the concepts of cognitive limitations and social ability and identified methods that are used to measure these concepts. The review has summarized the literature that examines the relationship between cognitive limitations and social ability, as well as literature that describes specific social abilities of individuals with a progressive dementia.

There is limited information on the relationship between cognitive limitations and social ability in individuals with moderate to severe dementia. This research adds to the

current body of knowledge available on this topic by systematically examining the relationship between the cognitive limitations and social ability including helping ability.

Chapter 3 describes the systematic method for examining the questions of this study.

## **CHAPTER 3**

### **Methods**

This research asked the following questions:

1. What is the relationship between cognitive limitations and social ability?
2. What is the relationship between cognitive limitations and helping ability?

This chapter addresses the two research questions. Sections on the research design, setting and inclusion criteria are provided first and followed by the measurement section. The measurement section includes demographic, activities of daily living (ADL), difficult behaviour, health, cognitive limitations and social abilities measures. A subsequent section presents the research procedure including ethical considerations, recruitment and data collection. The final section outlines the analysis in relation to each of the two research questions.

#### **3.1 Design**

The research design is cross-sectional with a convenience sample of residents with a progressive dementia living in 4 different long-term care facilities in Winnipeg, Manitoba. Data were collected by face-to-face interviews with residents and through chart audit.

#### **3.2 Setting**

The long-term care facilities were the personal care home (PCH) units at Riverview Health Centre (RHC), Deer Lodge Centre (DLC), Misericordia Health Centre (MHC) and Golden Links Nursing Home (GL). RHC has 228 personal care beds, 6 of these are regular units and 2 of these are special care units. DLC has 279 personal care beds, 55 of these are interim beds (2 units) and there are 36 beds designated as special care unit beds. MHC has 294 personal care home beds, 194 of these beds are interim

beds (temporary placement) and 100 are regular beds (permanent placement). GL has 88 personal care beds, 17 are designated for the special care unit and 2 are respite beds (available to family caregivers in the community who require a short break from caregiving). The care provided in interim care and permanent placement units is the same. Special care units have a different staff mix because the residents tend to have higher care needs than those in regular units. The majority of the participating residents in this study came from regular personal care beds. There were insufficient numbers of residents in the other categories to be able to determine if there were differences between the residents in terms of demographics or other factors related to institution or type of unit.

### **3.3 Sample and Inclusion Criteria**

Several inclusion criteria formed the basis of selection of the residents. The inclusion criteria were that residents must:

1. Be 65 years of age or older,
2. Be female,
3. Have a family member who is able to give consent,
4. Speak and understands English,
5. Have adequate hearing and vision (with or without aids),
6. Be medically stable (no new medications prescribed in response to an acute medical episode one week prior to recruitment and data collection),
7. Have been in the personal care home for at least two weeks prior to recruitment,
8. Have a diagnosis of Alzheimer's type dementia or dementia on the chart,
9. Have dementia as the main reason for the client being in a personal care home, and
10. Be able to smile, hold their head up and respond in simple sentences.

The individuals selecting the potential participants were asked to exclude those

residents with other neurological disorders that can cause dementia such as Cerebral Vascular Disease, Korsokoff's Syndrome or Parkinson's Disease.

The inclusion criteria are based on several considerations. The age and gender criteria reflect the demographics of personal care home residents. The ratio of females to males is approximately 2:1 in personal care homes in Manitoba (Manitoba Fact Book on Aging, 1996, p. 130). The gender criterion also reduces potential problems in the measurement of constructs in which gender bias is likely (e.g., depression).

Inclusion criteria for clinical presentation intended on capturing those residents with a progressive dementia. A defining medical diagnosis such as Alzheimer type dementia (AD) is not always found on resident's chart and those with a progressive dementia like AD are usually in the personal care home for cognitive limitations rather than difficulties with mobility. The exclusion of dementia due to other neurological condition was an attempt to facilitate homogeneity of the sample.

Having a family member facilitated the ability to attain proxy consent on behalf of the resident. To be interviewed, it was necessary that the resident be able to speak and understand English and not have vision and hearing deficits that would affect the reliability of the information that was collected. Residents were medically stable at the time of data collection. Medical stability was considered the absence of an acute illness in the week prior to data collection. Acute physical or mental illness can exacerbate cognitive deficits. Acute illness was indicated by the addition of a new medication to the resident in the last week. Any indication in the chart that the resident had not been well lately was also a cue to the investigator that an acute illness may have occurred. The nursing staff caring for the resident were solicited for their opinion of the resident's medical stability. Placement in personal care home units is stressful and requires a period



of adjustment so residents must have been at the long-term care facility for at least two weeks prior to recruitment.

The sample size of the research was 35. This sample size provides a power of .80 for a correlation coefficient with an alpha of .05. It provides a power of .75 for a chi-square contingency table test with a df of 2 with an alpha of .05. The higher the power of the study the less likely the results occur due to a type 2 error (no difference is found when there is a difference) while the lower the alpha the less likely that the results have occurred due to a type 1 error (a difference was found when no difference actually exists).

### **3.4 Measurement**

This section includes discussion of the following measures: demographics, difficult behaviour and activities of daily living (ADL), health, cognitive limitations, social ability and helping ability.

#### **3.4.1 Demographics**

Demographic data were collected from the resident's chart. This includes the resident's length of stay at the long term care facility (as calculated from the date of admission to to the date of data collection), age (as calculated from date of birth), marital status and education, ethnicity and religion (if available) (Appendix A).

#### **3.4.2 Behaviour and Activities of Daily Living (ADL's)**

Information on ADL activities and evidence of difficult behaviour were collected from the resident's chart. An information sheet was used to capture the information on both the resident's ADL activity and on behaviours that staff had identified in the chart as being difficult to manage. The ADL activities included dressing, bathing, toileting (bowel and bladder), eating and mobilizing. The resident was either independent with an activity (score 1) or required assistance with the activity (score 2) (Appendix A).

Difficult behaviors were either identified in the chart (score 1) or absent (score 2). For this research, difficult behaviours included wandering or pacing, verbal aggression or resistance to care.

### **3.4.3 Depression**

Information on the medical diagnosis and medications of residents were collected from the residents' charts (Appendix A). Two measures to describe depressive symptoms of the residents were used in research: the Geriatric Depression Scale (5-item version GDS) and the single, self-rated depression item (Appendix B).

This research examined social abilities. These abilities can be compromised when residents with AD are depressed. Residents with AD can be clinically depressed or demonstrate symptoms of depression. Unfortunately, depression can be overlooked in those with dementia (Tappen, 1995). Reports of depression among residents in long-term care vary but tend to be higher compared with community-based older adults. In long-term care, the prevalence of major depressive syndromes is 15-20%, minor depression is 25-40% and significant unhappiness and emotional suffering of 50% have been reported (Borson & Fletcher, 1997). Depression among the residents were measured using the 5-item GDS and the self-rated depression single item.

A measure of depression was the 5 item Geriatric Depression Scale (GDS). This is a shorter version of the original 30 item GDS (Yesavage & Brink, 1983) that has demonstrated reliability and validity in a study of older adults in long-term care and in the community. The items require responses of "yes" or "no" to statements of feeling. The original GDS has several shorter versions including a 15-item version and the 5-item version. For this research, the 5-item GDS was the preferred version because it took into account the fatigue and limited attention that can affect the reliability and validity of face-

to-face interviews with residents with AD. The 5-item version was developed by Hoyle et al. (1999) with a group of adults age 65 and older (n=74) who were attending a Geriatric Assessment clinic. These 5-items of the GDS exhibited the highest correlation coefficient with the diagnosis of depression (according to clinical standards of depression). The items had the best fit or a specificity of greater than .80 and a relative positive global diagnostic accuracy of .90 (Hoyle et al., 1999). The 5-items, answered by "yes" (score 1) or "no" (score zero) are:

1. Are you basically satisfied with your life?
2. Do you often get bored?
3. Do you often feel helpless?
4. Do you prefer to stay at home rather than going out?
5. Do you feel pretty worthless the way you are now?

Item #4 was modified to fit with long-term care residence to ask, by "Do you prefer to stay in your room rather than going out?" The range of score for the 5-item GDS is 0 to 5 and like other versions of the GDS it has a "cut-off" score for probable depression. A score of 0 or 1 indicates that the resident was not depressed and scores of 2 or higher suggested probable depression. Using this cut-off scoring, a sensitivity of .97 and specificity of .85 was reported (Hoyle et al., 1999). The alpha coefficient for internal consistency of the scale was .80. The 5-item GDS usually takes less than a minute to administer.

The second depression measure was the single self-rated depression question. The item asks, "Do you often feel sad or depressed?" and offers the choice of responses of "yes" (score 1) or "no" (score zero). In a study of 51 veterans, the 30 item GDS and the single question on self-rated depression were administered. The single question had a

sensitivity of .69 and specificity of .90 with 85% correct diagnosis of depression (Mahoney, Drinka, Abler, Gunter-Hunt, Matthews, Grenstein & Carnes, 1994).

#### **3.4.4 Cognitive Limitations**

Following the Disablement Model, cognitive limitations are defined as deficits in mental action caused by cognitive impairment. For this research, cognitive limitations were measured in two ways, first by using the Dementia Rating Scale (DRS) (Mattis, 1988) (Appendix C) and second by using the facial affect recognition item from the Abilities Assessment Inventory (AAI) (Dawson et. al., 1993) (Appendix D).

The DRS was selected to measure cognitive limitations of people with a progressive dementia for several reasons. The DRS measures low levels of cognition among older adults (Kluger & Ferris, 1991). The DRS consists of items commonly used by clinicians to detect dementia and ascertain the type of dementia. It is a cumulative scale with subscales that address specific areas of cognition. The DRS is used extensively and several studies have reported acceptable reliability and validity (Bennett, Nadler, Spilger, Rafalson, Abraham & Relkin, 1997).

The areas of cognition within the DRS are attention, initiation and perseveration, construction, conceptualization and memory. The attention subscale has 8 items with a scoring range of 0 to 37. The attention subscale items address auditory, visual, verbal and nonverbal attention. The tasks include a digital span task, a two stage command, a counting exercise, and tests of visual matching and verbal recognition. The initiation and perseveration subscale has 11 items with a scoring range of 0 to 37. These items require the individual to initiate and preserve on several verbal and nonverbal exercises. For example, the individual is asked to name as many supermarket items as he/she can in one minute. A nonverbal task involves repetitive hand movements.

The construction subscale has 6 items with a scoring range of 0 to 6. The major task is copying a design and the first design is geometric and complex. Simpler designs such as a circle are provided if more complex designs are not completed. The conceptualization subscale has 6 items with a scoring range of 0 to 39. This subscale consists of items that ask the individual to identify similarities and differences among objects and to create a sentence. The memory subscale has 5-items with a scoring range of 0 to 25. The memory subscale taps orientation to person, place and time, verbal recall and recognition and visual memory. The recall and recognition items refer to remembering previous subscale items, such as recalling the sentence that the individual created for the conceptualization subscale task.

All of the subscale items require the individual to perform tasks that are presented in a graduated format so that the most difficult task comes first. When the individual carries out the first task correctly, the score is the maximum. If the task is not correctly carried out, then tasks of lesser difficulty are presented. The number of items for each individual thus varies and the time required to finish the DRS also varies. The DRS can usually be administered within 15 to 45 minutes but there is no imposed time restriction.

The range of the cumulative DRS score is 0 to 144. According to Mattis (1988), normal older adults tend to score 140-144. Several studies have suggested cut-off scores related to possible dementia and probable dementia, and mild, moderate or severe dementia. The cut-off score for possible dementia is 137 (Schmidt et al., 1994, Vitaliano et al., 1984) but it has been suggested that a lower cut-off score of 130 be used for individuals who have 4-9 years of formal education (Schmidt et al., 1994). The specificity with a cut-off score of 122/123 is .84 and the sensitivity is .87 in detecting probable dementia (Fama et al., 1989, Salmon et al., 1989). Paulsen et al. (1995) suggested cut-off

scores for mild dementia (129), moderate dementia (117) and severe dementia (102). Similarly, each subscale has a cut-off that represents a deficit in a cognitive area. The subscale cut-offs were developed by Mattis (1988) representing 2 standard deviations below the mean, and used by Goldstein (1997) were as follows: 32/37 (attention), 29/37 (initiation), 4/6 (construction), 32/39 (conceptualization) and 19/25 (memory). Slightly different cut-offs are suggested by Struss et al. (1996), attention, 33/34, initiation and perseveration, 26/27, memory 17/18, construction 5/7 and conceptualization was 33/34.

Reports of reliability (test-retest and internal consistency) and discriminant validity have been published. The test-retest reliability score for the cumulative scale was .97 with the following subscale values of .61 (attention), .89 (initiation) .83 (construction), .94 (conceptualization) and .92 (memory) (Vitaliano et al., 1984). Split-half reliability for the DRS cumulative scale was .90 and internal consistency has been recorded as .75 and .95 (Vitaliano et al., 1984).

Discriminant validity has been demonstrated with a community sample of older adults with AD (n=254) and cognitively intact older adults (n=105) (Monsch et al., 1995). Using a DRS cut-off of 129 (mild dementia), 91% of those with AD and 93% of those who were cognitively intact were correctly identified. The memory and initiation subscales ranked highest in discriminating between older adults with AD and cognitively intact older adults. Discriminant validity has also been demonstrated with comparison samples of individuals with Huntington's Disease (HD) (Paulsen et al., 1995, Salmon et al., 1989) and with individuals with Lewey body dementia (Conner et al., 1998). Compared with individuals with AD, those with HD performed significantly poorer in initiation and perseveration, and construction tasks. Individuals with Lewey body

dementia (type of dementia associated with Parkinson like symptoms) performed relatively better on the memory subscale and poorer on the initiation and perseveration subscale. DRS has demonstrated sensitivity to changes in a progressive dementia severity (Salmon et al., 1990).

The second measure of cognitive limitation is the facial affect recognition item from the Abilities Assessment Inventory (AAI) developed by Dawson et al. (1993). The AAI is multi-dimensional instrument designed to be administered by clinicians. The goal of the AAI is to provide information on the intact abilities of an individual with dementia. Four subscales make up the AAI: Self-Care Abilities, Social Abilities, Interactional Abilities and Interpretive Abilities. The facial affect recognition item is part of the Interpretive Abilities subscale. Interpretive ability is the ability to "derive meaning from the external world" (Dawson et al., 1993, p. 102). Specifically, the facial affect recognition item is constructed to measure the ability to detect emotions through facial expression (Appendix D).

This AAI and its subscales have undergone reliability and validity testing. The psychometric properties of the AAI were studied with a sample of 172 male residents, 60 with no cognitive impairment and 112 with cognitive impairment. The residents had different types of dementia, including AD, multi-infarct dementia and Korsakoff's dementia. The cumulative scale test-retest coefficient has been reported as .98 with interrater reliability of .99.

The procedure for administering the facial affect recognition item followed a step-by-step process and involved three photographs of the same person depicting facial expressions of sadness, happiness and anger. The participating resident was shown each face one at a time and asked each time if the person in the photograph was sad, happy or

anger and this descriptor was recorded. If the resident accurately identified the pictures as sad, happy or angry a score of 1 one was attained, if the resident did not accurately identify the emotion in the picture the score attained was 0. The range of scores on the facial affect recognition item was 0-3. Reliability of the photos to depict the three emotions were confirmed with 10 cognitively intact individuals.

### **3.4.5 Social Ability**

For this research, social ability was measured using the Social Abilities Subscale (SAS) of the AAI (Dawson, 1993) (Appendix E) and the two helping ability items (developed by Tallman, 2000) (Appendix F).

The SAS (Dawson et al., 1993) contains 3 categories of social abilities (specific abilities) including the ability to give and receive attention, engage and participate in conversation, and appreciate humor. The first specific ability is described as giving and receiving attention by Dawson et al. (1993) and has four items for a total score range of zero to 14. The first item involved the investigator greeting the participating resident with "hello" and scoring according to a set of responses. A verbal reply is scored 4, a smile is scored 3, eye contact is scored 2, muttering is scored 1 and no response is scored zero. The second item involved rating the individual's response "how are you?" with a verbal reply scored 3, unclear verbal reply scored 2, non-verbal reply scored 1 and no response scored zero. The third item taps the individual's response to the investigator introducing herself. The resident's response of repeating the investigator's name or own name is scored 4, facial response is scored 3, body language (non facial) is scored 3, mumbling is scored 1 and no response is scored zero. The fourth item involved the resident's response to the investigator offering a handshake. The resident's response of taking the hand was scored 3, allowing her hand to be taken was scored 2, letting go of



the hand was scored 1 and no response was scored zero.

The second specific ability of the SAS measured the ability of the resident to engage or participate in conversation. There are 4 aspects of the resident's response that were measured. The first aspect was the ability of the resident to stay on topic. If the resident stayed on topic the score was 2, if the resident related improbable events the score was 1, if the resident did not respond to the topic the score was 0. The second aspect of the ability to engage and participate was the extent to which the resident responded verbally. If the resident responded with distinct verbal response, the score was 2, if the resident responded with indistinct verbal response the score was 1, if the resident responded with no verbal response the score was 0. The third aspect of the ability to participate in a conversation was a nonverbal response. If the resident took turns when having a conversation the resident attained a score of 1, if they did not take turns they scored 0. The fourth aspect also measured a nonverbal response of the resident. The resident scored 1 if she looked, listened, or nodded during the conversation and scored 0 if she did not. The specific ability to engage and participate in conversation had a range of 0-6.

The humour appreciation item consisted of two parts, one involved the investigator showing a cartoon and the other involved the investigator telling a joke. The cartoon (Appendix E) depicted a hunter with a rifle and a duck carrying a dog in his bill back toward the hunter. If the resident's responded to the cartoon by laughing out loud or if they made relevant comments the score was 3. Laughing quietly scored 2, smiling scored 1 and no response scored zero. The joke is given below.

"A kangaroo walked into a bar and asked the bartender for a beer. The bartender gave the kangaroo a beer and said "that will be \$10 dollars." Later the bartender returned and said, "we don't get many kangaroos in here." The kangaroo said, "I'm not surprised, at these prices."

The resident's response was scored as 3 if she laughed at the punchline or made relevant comments, she scored 2 if her facial expression changed at the punchline, scored 1 if her response was inappropriate (crying or anger) and zero, if there was no response. The humour appreciation specific ability had a range of score of 0-6.

The SAS has a scoring range of zero to 26. Psychometric properties of the SAS scale have been evaluated by Dawson et al. (1998) and Rivera (1998). In a 1998 study, Dawson et al., demonstrated SAS reliability and validity with a sample of 172 male residents living in an extended care department of a hospital. Test-retest reliability was .93, the interrater reliability was .99 and the internal consistency was .91. Concurrent validity was demonstrated between social ability and two disability scales. Discriminant validity was shown with a significantly higher score among cognitively intact individuals compared with cognitively impaired individuals (Dawson et al. 1998).

In Rivera's (1998) study, the psychometric properties of the SAS were demonstrated on a sample of 60 female medical/surgical patients. Thirty patients were cognitively impaired and 30 were cognitively intact. Test-retest reliability was .95, inter-rater reliability was 100% and internal consistency for the three items was .75. A significant relationship between a widely used cognitive screening tool (the Mini-Mental Status Exam) and the SAS demonstrated concurrent validity. Content or face validity was evaluated by two content specialists (Dawson et al., 1998).

#### **3.4.6 Helping Ability**

An attribute of social abilities that was not captured in the SAS but that was of interest to this research was helping ability. Two helping ability items were developed by the investigator following the graduated format of scored responses developed in the SAS (Appendix F). The two items intended to solicit responses on the ability of individuals

with a progressive dementia to engage in helping behaviour. The items tapped verbal and physical helping ability and were constructed to provide the participating residents with opportunities to listen supportively or assist with picking up a dropped object (a book). The items were reviewed by Ms. P. Dawson. She felt there was a fit of the item with the SAS ( February 23<sup>rd</sup>, 1999 e-mail correspondence).

The verbal-helping item has 2 statements. Statement 1 is "I feel sad today" with 5 possible responses. If the resident asks for elaboration of the details of why the person feels sad she scored 4, a verbal empathetic response such as "that's too bad" scored 3, a verbal utterance such as "oh" scored 2, a nonverbal response (such as a sad facial expression) scored 1 and no response scored zero. These responses were followed by statement 2. In statement 2 the investigator states that she was feeling sad because a cat she had for 20 years died last night. The response to this second statement followed the same scoring format as that of the first statement. These two parts of the helping item (verbal) have a scoring range of zero to 8.

The physical-helping item was developed to solicit helping behaviour for individuals with a progressive dementia who were less verbally responsive but who had retained physical abilities. Discussion with Ms. P. Dawson (personal communication, February, 1999) lead to the development of this item. The item involved the investigator 'accidentally' dropping a book in full view of the participating resident while leaving the interview. The categories of helping in this case were either, yes they were helpful by picking up the book or by letting the investigator know that she had dropped a book or no helping response because the resident didn't respond to the dropping book. Early in the process of data collection it was found that there were too many factors that infringed on the accuracy of this item to measure physical-helping ability. The cause of this concern

over accuracy of the item to measure helping ability was that residents who had just been interviewed privately and returned to a common area were consistently not observing the book fall or those that were left alone did not respond because of sensory deficits. It was speculated that because of the change of environment and the increased stimulation in the environment in the common area the resident did not respond to the dropping book. It became clear that not responding to the dropping book was a poor indicator of not helping therefore the physical-helping item was deleted. For the rest of the discussion the helping item refers to the verbal-helping item.

### **3.5 Study Procedure**

This section presents and discusses the ethical issues, the recruitment protocol, and data collection and analysis procedures.

#### **3.5.1 Ethical Issues**

Procedures for recruitment and data collection follow the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS) (1998). Moderate to severely demented (stage 5 and 6) residents are a vulnerable group and the TCPS does address research with vulnerable populations. A quote from the Code of Ethical Conduct indicates that "To deny persons access to research participation out of fear of exploitation of specific groups of persons is to avoid rather than accept and practice ethical responsibility" (p. 5.4). There are two major issues when conducting research on individuals with a progressive dementia. These are the issue of free and fully informed consent and the issue of the risk/benefit ratio when conducting the research (Fisk, Sadovnic et al., 1998).

Obtaining free and fully informed consent is a main principle when conducting research on human subjects. Individuals with a progressive dementia may be unable to

understand the concept of research and the risks that they are being asked to take when participating in the research. The participating subject should have the opportunity to learn about the nature of the research, the consequences of being involved and a clear indication that they can stop being involved at any time in the research. If the individual is incapable of making a decision or understanding the consequences than a third party (usually family) can provide proxy consent. The process of attaining third party consent must involve the conditions described in Article 2.4 (Ethical Conduct for Research Involving Humans, p.2.5).

Family consent for the individual with dementia is the method of ensuring that the rights to be or not to be involved are respected. In this research, it was argued that the overall benefit outweighed the minimal risk. The benefit is the contribution that this knowledge could make to the quality of life to individuals with cognitive impairment. The risk is defined by University of Manitoba, policy #1406 in Human Subject Research, Ethic Protocol Submission Form. Minimal risk is defined as a risk that someone would have during the course of normal interactions with others. These normal interactions include the risks that occur while undergoing a routine physical or psychological exam by a professional. The administration of the SAS and the helping ability item were no more than what a person might encounter in day to day life, therefore it is argued that the risk was minimal and the benefit was high.

### **3.5.2 Protocol for Recruitment**

The protocol for recruitment included the following steps:

1. Accessing the facility: The appropriate person in each facility was contacted to determine if they were amenable to a research study being conducted at the facility. Each institution required a slightly different process for attaining access. For

example, RHC requested an application with the research proposal. The application and proposal were assessed by an RHC Ethics Committee. The committee's concerns were addressed in writing by the investigator. DLC had an Access Committee who reviewed the application to determine if the facility could accommodate the research. When accessing MHC the Director of Nursing approved access to the facility at large and a meeting was held with the managers of the units to determine if they would permit the accessing residents on their unit. Some of the unit managers allowed this and others did not allow access on the unit they supervised. The Director of Care of GL allowed access to this facility after a brief description of the project and staff involvement was provided to her.

2. Providing Information: The investigator provided information to the managers and staff on the units with potential residents describing the criteria, their involvement and consent information. The information to staff was in the form of a written sheet (Appendix G). The investigator made herself available to do an information session on the project at the facilities request.
3. Identifying the potential participating resident: The manager of the units, designated staff, Director of Care (in GL) or research assistant identified the potential residents and contacted the family or potential resident asking their permission to give their name to the investigator. The research assistant was only involved with identifying and attaining consent at MHC. When the research assistant contacted families she followed a script written by the investigator (Appendix H).
4. Signing Consent: The investigator or research assistant contacted the family member by phone or in person to provide further information and request their permission to have their family member interviewed by the investigator. If the family agreed by

phone, a time was arranged for the family member to sign the consent (Appendix I).

5. Obtaining permission from the participating resident: At the time of data collection the investigator asked the resident if she would mind assisting the investigator with a research project she was doing. Throughout the interview the investigator would ask if the resident still wanted to continue. There were a few residents who indicated that they did not want to continue and therefore the interview was stopped. There were a few residents who became agitated and therefore the investigator decided to stop the interview.

### **3.5.3 Data Collection**

The process of attaining the sample for the study involved gaining access to 4 different long-term care facilities in Winnipeg. Though the process for attaining access to the residents for the study was different in each of the institutions the integrity of the ethical principles and the Personal Health Information Act were maintained when accessing residents in each institution. Chart 1 (Summary of Data Collection) describes the number of residents who were asked to participate and the number of residents who actually participated in the study.

**CHART 1**  
**Summary of Data Collection**

Facility	Number of Personal Care Home Beds	Number of Residents Identified as Meeting the Criteria	Number of Families that Signed Consent	Number of Residents that Completed Interview
Deer Lodge Centre	279 PCH	7	6	5
Riverview Health Centre	228 PCH	17	14	14
Golden Links Lodge	88 PCH	14	10	9
Misericordia Health Centre	294 PCH	14	8	7

Data were collected by the investigator. The investigator is a Registered Nurse and practices in clinical geriatrics and has both research and clinical experience in administering standardized instruments as well as communicating with individuals with moderate to severe dementia. The investigator's thesis supervisor has conducted research in long-term care facilities for about ten years.

### **3.5.4 Protocol for Data Collection**

The investigator conducted the interviews with the residents and collected the data from the resident's chart. Collection of data involved a face-to-face structured interview administering the instruments in the study. The face-to-face interviews were conducted in a private area on the resident's unit. The first instrument administered to the resident was the SAS, the second instrument administered was the DRS, the third one was the facial affect recognition item, the fourth one was the depression screening scales, and the last one was the helping item. In order to practice and ensure the feasibility of the interview approach, the investigator administered all of the tests to 4 cognitively intact individuals. The investigator considered the first two participating residents as pretests



and evaluated the feasibility of the interview approach after the second interview with a resident. It was considered at that time that the protocol for the administration of the various scales and screening tools in this study was feasible.

### **3.6 Data Analysis**

#### **3.6.1 Descriptive Data**

Sociodemographic data were collected and aggregated. Univariate analyses (frequencies) were carried out for ordinal/interval variables and for nominal variables. Univariate descriptive statistics included means, range, and standard deviation. Univariate statistics were used to describe the chart data including ADL's, the difficult behaviours, the medications and the medical diagnosis of the residents. Data from the depression scale (5 question form of the Geriatric Depression Scale and the single item) were aggregated as frequencies. Bivariate non-parametric statistics were used to analyze if there was a significant relationship between the screens for depression and SAS or the DRS as well as if there was a relationship between medication use and SAS and DRS. The tests used were the Spearman's rank correlation coefficient and the Mann-Whitney U Test. All scales and subscales were tested for internal consistency (Cronbach's alpha). Bivariate non-parametric analysis was carried out to address the two research questions.

#### **3.6.2 Research Question 1**

##### **1. What is the relationship between cognitive limitations and social ability?**

The statistical approach to detecting a relationship between cognitive limitations (measured by the DRS and facial recognition item) and social abilities (SAS) was a correlation analysis using the Spearman's rank correlation coefficient ( $\rho$ ).

#### **3.6.3 Research Question 2**

##### **2. What is the relationship between cognitive limitations and helping ability?**

Similar to research question #2, the analysis of the relationship between cognitive limitations (DRS and by the facial affect recognition item) and helping ability (two items) entailed using Spearman rank correlation coefficient ( $\rho$ ).

### **3.7 Summary**

This chapter has described the methods used to address the research questions. The research questions examined the relationship between cognitive limitations and social ability including helping ability. Answering these questions involved a systematic approach for gathering the data that integrated ethical considerations. The methods included specifying the inclusion criteria, the setting in which the research occurred and the demographic information collected. This chapter also presented the measures used to describe the concepts of interest.

The measures used in this study are the DRS, the SAS, the facial affect recognition item, the helping item, and the 5-item Geriatric Depression Scale and the single, self-rated depression item. The DRS has been used for a number of years in research to describe the cognitive deficits of subjects. It has proven validity and reliability. The other measure of cognitive limitations was the facial affect recognition item. This item was selected out of larger inventory of items meant to measure the ability of individual with dementia to interpret their environment (Dawson et.al., 1993). A relatively new measure of social ability (SAS) was used in this study. The SAS has been used to describe the retained abilities of individuals with dementia in one study (Wells & Dawson, 2000) and it has proven reliability in a few studies (Dawson et al., 1998, Rivera, 1998). Helping ability was measured using a new item developed for this research. The 5-item Geriatric Depression Scale and the single, self-rated depression item were used to measure possible depression.

The study procedure section described the ethical considerations involved in subject recruitment and data collection. The protocol for data collection included describing the order in which the measures were administered in the face-to-face interview. The data analysis section outlined the statistical methods that were used to handle the sociodemographic data and to address the two research questions. The next chapter describes data analysis.

## **CHAPTER 4**

### **Research Findings**

The purpose of this research was to examine the relationship between cognitive limitations and social ability, including helping ability, of female residents with a progressive dementia who reside in long-term care facilities (personal care home units).

Two questions guided the research:

1. What is the relationship between cognitive limitations and social ability?
  - a) What is the relationship between cognitive limitations as measured by the Dementia Rating Scale (DRS) and social ability as measured by the Social Abilities Scale (SAS)?
  - b) What is the relationship between cognitive limitations as measured by the facial affect recognition item (FA) of the Abilities Assessment Inventory and social ability as measured by the Social Abilities Scale (SAS)?
2. What is the relationship between the cognitive limitations and helping ability?
  - a) What is the relationship between cognitive limitations as measured by the Dementia Rating Scale (DRS) and helping ability as measured by the helping ability item (HI)?
  - b) What is the relationship between cognitive limitations as measured by the facial affect recognition item (FA) of the Abilities Assessment Inventory and helping ability as measured by the helping ability item (HI)?

Chapter 4 presents the results of the data analyses used to answer the two questions.

First, the chapter describes the statistical tests used to analyze the data followed by a

description of the research participants. The third section discusses findings related to depression and some of the issues associated with measuring depression in long-term care. The fourth and fifth sections present, respectively, the psychometric properties of the scales and frequency analysis of the major variables of interest: cognitive limitations, social ability and helping ability. Section six provides findings on the two research questions. The final section is a brief summary of the chapter that leads to chapter five.

#### **4.1 Statistical Tests**

In order to achieve sufficient statistical power, a sample of 35 residents was required. This sample size provided a power of .80 with a two tailed significance of .05 when using correlation coefficients. The statistical power of a test is defined as the probability of not detecting a true difference (type II error) while significance is defined as the probability that findings could have occurred by chance alone (type I error).

Bivariate analysis of the Social Ability Scale (SAS), the Dementia Rating Scale (DRS), the facial affect recognition item (FA) and the helping ability item (HI) indicated non-normal distributions. Given the sample size and non-normal distribution, non-parametric statistical tests were appropriate. The following tests were selected:

**Spearman's Correlation Coefficient (rho):** This test measures the extent of a linear association between two ordinal level variables.

**Mann-Whitney *U* Test:** This test measures the differences between two groups when the data for the two groups are measured on an ordinal scale. Although ordinal measures are used with this test, an underlying continuous distribution is assumed.

**Chi Square:** This test is used to determine the number of responses, objects, or people that fall into two or more categories. An expected number is based on chance (equal opportunity) and the actual or observed number is compared with the expected number to determine statistically significant differences.

#### **4.2 Description of Participants**

The data describing the 35 female participants were aggregated into frequencies and measures of central tendency (where applicable) for age, education, length of stay in the long-term care facility, medical diagnoses, medications, ethnicity, marital status, family status, behavioural issues, ADL status and feelings of depression.

The average age of participants was 86.2 years (standard deviation of 7.0 years) with a range was 69-99 years (Table 1). Statistics from the Manitoba Fact Book on Aging (1996) indicated that the age range of woman in personal care homes was 85-94 years. Thus, the research participants generally reflected the Manitoba personal care home population but with a wider age range.

**Table 1 – Participants' Age**

<b>Age Group</b>	<b>n =</b>	<b>%</b>
79 – less	4	11.5
80 – 84	12	34.1
85 – 89	7	20.0
90 – 94	8	22.8
95 – greater	4	11.5

The research participants tended to have more years of formal education compared with Manitoba figures presented in the Manitoba Fact Book on Aging (1996). The

Manitoba Fact Book on Aging indicated that the Manitoba population of woman age 65 years and older with grade 9-12 education was 38.3 % while for these research participants, it was 68%. The percentage of participants with university education was somewhat less than the Manitoba population described in the Manitoba Fact Book on Aging (12% versus 22%). The average number of years of formal education for participants was 11 years with a range of 5-18 years (Table 2).

**Table 2 - Participants' Years of Formal Education**

<b>Years</b>	<b>n =</b>	<b>%</b>
Grade 9 or less	5	20.0
Grade 9 – 12	17	68.0
Grade 12 or more	3	12.0

Ethnicity refers to the “ethnic origin or cultural group to which our ancestors belonged.” (p. 26, Manitoba Book on Aging). Of the 35 participants, only 28 had chart information on ethnicity (see Table 3). Most often, this information was given in the social work report or the recreation assessment sheet. The Manitoba Book on Aging (1996) indicated that 37.2 % of older Manitobans described their ethnic status as British. For these research participants, “British” was also the most commonly identified group (Table 3).

**Table 3 - Participants' Ethnicity**

<b>Ethnic Status</b>	<b>n =</b>	<b>%</b>
Canadian	2	8.0
British Isles	13	46.0
Eastern Europe	7	25.0
Others	6	24.0

Note: n = 28 because of missing data

Only 22 of the 35 participants had a religious affiliation recorded on their chart.

The research participants' religious affiliations were consistent with the general population in Manitoba and the largest groups were Protestant (47.3%) and Catholic (14.3 %).

The research participants were also fairly representative of the Manitoba population in terms of marital status. About 3/4 (73.5%) were widows, 17.6 % were married, 4% were single and 8% were divorced or separated. This compares to the Manitoba population of women age 75 and older as described in the Manitoba Book on Aging (1996) where 59.5 % of women age 75-84 and 81.6 % of women age 85 and older are widows. Similar comparisons with the Manitoba population could be made about the small percentage of participants who were divorced or single.

Almost all (94%) of the participants had children and the remainder (6%) had a relative or friend assigned to make decisions on their behalf. This characteristic is an artifact of the inclusion criteria which stipulated the presence of a family member who could provide consent.

Participants' length of stay varied from 53 to 1998 days with an average of 512.2 (standard deviation=508.1) (Table 4). The length of stay for participants was calculated from the date of admission to the date of data collection.

**Table 4 - Participants' Length of Stay**

<b>Length of Stay</b>	<b>n =</b>	<b>%</b>
100 days or less	8	22.8
100 – 399 days	10	28.6
400 – 999 days	11	31.4
1000 days or more	6	17.1



Most participants had several medical diagnoses listed on their charts. The average number of diagnoses were 4.5 (standard deviation=1) with a range of 2 to 7 diagnoses. The frequency and percentage of diagnoses by body systems are described in Table 5. Past surgeries and remote fractures (occurred several years ago) are not listed because of diminished relevance to current health status. Mental health diagnoses were almost always identified as depression. Examples of diagnoses related to the cardiovascular system were high blood pressure, ischemic heart disease, congestive heart disease, chronic obstructive pulmonary disease, trans-ischemic attacks and peripheral vascular disease. Musculoskeletal diagnoses included osteoarthritis and osteoporosis. Gastrointestinal/genitourinary diagnoses included gastric reflux disease, diverticulitis, ulcer, esophageal reflux and constipation. The primary endocrine diagnosis was diabetes type II.

**Table 5 - Participants' Diagnoses**

<b>Participants Diagnoses</b>	<b>n =</b>	<b>%</b>
Mental Health	9	25.7
Cardio-Vascular	28	80.0
Musculoskeletal	21	60.0
Gastro-intestinal/Genitourinary	13	37.1
Endocrine system	7	20.1

Table 6 presents the dementia-related diagnoses of dementia found on participants' charts. Although the inclusion criteria specified "dementia present" and the program managers identified only those residents with a progressive dementia, two participants' charts did not have a dementia-related diagnosis. Since charts do not always accurately include the diagnosis of dementia and because for these two participants, there

were no other focal signs (evidence of stroke) or evidence of dementia for other causes, they were included in the research.

**Table 6 - Participants' Dementia-Related Diagnoses**

<b>Dementia-related Diagnoses</b>	<b>n =</b>	<b>%</b>
Alzheimer's Disease	18	51.4
Dementia and Progressive Dementia	11	30.5
Cognitive Impairment	4	11.4
No Dementia Diagnoses	2	5.7

The average number of prescribed medications for the participants was 5.4.

Medications that were prescribed as necessary but not on a regular basis were not included in Table 7 unless they had been administered in the 2 weeks prior to data collection. Given the psycho-social basis of the two research questions, data collection was primarily focused on medications related to behaviour and emotional state, that is, the use of antidepressants, antipsychotics, antianxiety and memory enhancing drugs.

**Table 7 - Participants' Medications for Mental Health**

<b>Participants Medications – (Mental Health)</b>	<b>n =</b>	<b>%</b>
Antidepressants	18	51.4
Antipsychotics	10	28.6
Anti-Anxiety	7	20.0
Memory Enhancer	3	8.6

Data were collected on participants' activities of daily living (ADL) and the necessity for at least some assistance with ADLs (Table 8). The extent to which assistance was required was not captured in this study. Almost all of the participants required some assistance in bathing and more than one-half of the participants required

assistance with toileting. Though assistance was identified for eating, the primary assistance was for the meal to be set up, for example, by removing lids from containers. Less than one-half had difficulty with mobility and this makes sense in view of the inclusion criteria that stipulated cognitive impairment as the primary reason for placement in a long-term care facility.

**Table 8 - Participants' Requiring Assistance with ADL's**

<b>Assistance with ADLs</b>	<b>n =</b>	<b>%</b>
Dressing and bathing	32	91.0
Toileting (bladder)	22	62.9
Toileting (bowel)	14	40.0
Eating	24	68.6
Transfers	17	48.6
Walking	13	37.1

About half (54%) of participants had a description of difficult behaviour on their charts although the extent or frequency of this behaviour was not generally recorded. The most often described difficult behaviour was "resistance to care" which includes situations where participants had refused assistance with ADLs. Other difficult behaviours were wandering, pacing, verbal aggression, being rude, anxiety, agitation and physical aggression.

### **4.3 Depression**

Given the psycho-social nature of the research questions, it was important to address how feelings of depression might relate to cognition and the expression of social ability and helping ability. Initially, two measures were used to measure feelings of depression: the 5-item Geriatric Depression Scale (5GDS) and the single question on self-rated depression. For the 5GDS that was originally used by Hoyl et al. (1999), a cut-off

score of 2 or more (from a possible score of 5) had been used to screen individuals who required further assessment for clinical depression. Those who scored 1 or less were not referred for further assessment. In terms of participants in this research, almost half (45.7%; n=16) scored 2 or more out of a possible score of 5. Table 9 presents the frequency and percentage of “depressed responses” for the individual items of the 5GDS, the single question on self-rated depression and the cut-off score of 2 or more.

**Table 9 - Participants’ “Depressed Response” on 5GDS Item and Cut-Off and Single Question**

<b>Depressed Response</b>	<b>n =</b>	<b>%</b>
No – Satisfaction with life	9	25.7
Yes – Often bored	14	40.0
Yes – Feeling helpless	14	40.0
Yes – Prefer to stay in room	6	17.1
Yes – Feeling worthless	13	37.1
Yes – Single question	13	37.1
Falling in depressed group (cut-off)	16	45.7

While Hoyl et al. (1999) reported an internal consistency Cronbach’s alpha coefficient of .80 for the 5GDS, this research reports .73 which is still acceptable. Cronbach’s alpha ranges from 0 to 1.0 and indicates how much the items in an index are measuring the same thing. After closer examination of the items that make up the 5-item GDS, it appeared that one item, “Do you prefer to stay in your room rather than going out?” might be measuring something different. This item had to be altered from its original form (“Do you prefer to stay at home rather than going out?”) to fit the long-term care context and a response of “yes” is typically scored as “depressed” response. However, in long-term care facilities, the context of “home” and “room” may be

divergent. In long-term care facilities, a resident's room is an area of privacy and preferring to stay in one's room may reflect a healthy need for privacy rather than a desire for seclusion. When the "room" item in the 5GDS was reverse scored, that is, when "yes" was scored as a "non-depressed" response, the alpha coefficient dropped to .68. When the "room" item was deleted, thus creating a 4-item GDS, the alpha coefficient increased to .81. Clearly, there is a problem with the item and it may indeed be an issue of context specific to a long-term care facility setting.

Compared with the cut-off score of the 5-item GDS indicating that almost half (45.7%;  $n=16$ ) of the participants screened positive for depression, the single question for self-rated depression indicated that 37% of participants reported often feeling sad or depressed. As stated earlier, participants' medical chart data indicate mental health diagnoses that were primary diagnoses of depression. As indicated in Table 10, when comparing the four measures of depression, there were no significant relationships between the medical diagnosis of depression and the other measures. This may relate to the lack of currency of the medical diagnosis on the chart or that treatment in the form of anti-depressants had been put into place. The significant relationship among the 4-item GDS and the 5-item GDS cut-off is to be expected because items are from the same pool. The significant relationship between the 4-item GDS and the single question for self-rated depression. ( $p>.0001$ ) seems reasonable.

However, of concern is the validity of these measures when used in long-term care facilities with female residents with a progressive dementia. At best, both the 5-item GDS and the single question for self-rated depression are screening and not diagnostic tools.

The diagnostic measure, that is medical diagnoses on the charts, is suspect in terms of currency. Hoyl et al. (1999) reported a diagnostic accuracy of .90 for the 5-item GDS with out-patients in a geriatric clinic. The single question for self-rated depression has been reported to have 85% diagnostic accuracy in a population of 51 veterans males (Mahoney et al., 1994). These measures may not work as well with residents of long-term facilities because of contextual features. The prevalence of major depressive syndromes in nursing homes has been identified as 15-20%, minor depressions as 25-40% and significant unhappiness and emotional suffering as 50% (Borson & Fletcher, 1997). It seems likely that the 5-item GDS and the single question for self-rated depression reflect unhappiness and dissatisfaction rather than clinical depression.

**Table 10 – Relationship between Depression Screening Tools/Medical Diagnosis of Depression**

<b>Depression item</b>	<b>Single Item</b>	<b>5GDS cut-off</b>	<b>4GDS</b>	<b>Medical diagnosis</b>
Single item		Chi-Square p<.0001	Mann-Whitney p<.0001	Chi-Square p=.783
Depression vs Non Depression	Chi-Square p<.0001		Mann-Whitney p<.0001	Chi-Square p=.929
4GDS	Mann-Whitney p<.0001	Mann-Whitney p<.0001		Mann-Whitney p=.719

In order to address how feelings of depression might relate to the cognitive limitations (as measured by the Dementia Rating Scale and the facial affect recognition item), social ability and helping ability, appropriate statistical tests were conducted (Table 11). There were no statistically significant relationships among cognitive limitations,

social ability and helping ability with the 4-item GDS, the single question for self-rated depression and medical diagnosis of depression.

**Table 11 - The relationship between DRS, SAS, FA, HI and Screens for Depression, Medical Diagnosis of Depression and Medications for Mental Health**

<b>n = 35</b>	Depression vs. Non-Depression Mann-Whitney	Single item Mann-Whitney	4-item Depression Spearman's rho	Medical diagnosis on chart Mann-Whitney	On anti-depressants Mann-Whitney	Anti-psychotics Mann-Whitney	Anxiolytics Mann-Whitney
DRS	n=.766	n=.347	n=.78	n=.126	n=.960	n=.648	n=.695
SAS	n=.056	n=.281	n=.063	n=.308	n=.960	n=.589	n=.313
Facial Affect	n=.707	n=.355	n=.875	n=.884	n=.884	n=.382	n=.835
Helping Item	n=.769	n=.722	n=.546	n=.606	n=.606	n=.834	n=.190

#### 4.4 Psychometric Properties

Internal consistency alpha coefficient estimates (Cronbach's alpha) were done on the Social Abilities Subscale (SAS), Dementia Rating Scale (DRS) and its subscales.

Test-retest reliability of the Helping Item, a new measure for this research was also conducted.

The SAS achieved an internal consistency alpha of .74. This compares to the internal consistency attained by Rivera (1998) of .75 with a sample size of 60 older woman (from hospital sample), 30 unimpaired and 30 with cognitive impairment and an internal consistency reported by Dawson et al. (1998) of .91 (n=112, men living in extended care). Internal consistency alpha coefficient (Cronbach's alpha) for the Dementia Rating Scale was .91 with subscales ranging from .56 to .88. The lowest alpha was for the initiation and perseveration subscale and the highest was for the construction

and attention subscale. The alpha coefficients reported in the Professional Manual describing the Dementia Rating Scale (1988) from Vitaliano et al. (1984) ranged from .75 (memory subscale) to .95 (attention and conceptualization subscale). Vitaliano et al. (1984) were reporting from a study of 57 older adults (age 53 – 88) who were placed into categories of mild impairment, moderate impairment and no impairment.

The helping ability item initially involved two sources of information on helping ability: a verbal-helping item and a physical-helping item. The physical-helping item involved the investigator dropping a book while leaving at the end of the interview and then observing if the participant pointed out the book or offered to pick it up. Early in data collection, it became clear that the physical-helping item responses were dependent on the participant's being able to focus her attention on the investigator as she left. It seemed that attention was sometimes hampered by nearby activities (in the vicinity of the interview) that were distracting to the participants. Given the difficulty in providing a standardized approach, it was decided to delete the physical-helping item.

The verbal-helping item (HI) consisted of two statements made by the interviewer (helping statement 1 and helping statement 2). Helping statement 1 was "I am sad" and helping statement 2 was the explanation for the sadness, that is, "I am sad because a cat I had for 20 years died last night." This item was developed specifically for this research in order to tap helping ability. Test-retest reliability was done with 5 participants. Correlation between the two statements was tested and construct validity was evaluated by examining the relationship between the helping ability item and the SAS and individual items.



Test-retest on 5 participants demonstrated general consistency (Table 12) between the initial score and the second score. Out of a possible score of 4 for each statement, participants' responses were compared. The score for one participant was exactly the same. Two participants improved somewhat while one improved a great deal. One participant did slightly poorer. Overall for 4 of the 5 participants, there was reasonable stability. The one participant who improved a great deal likely did so because fatigue was less of a factor at the second time.

**Table 12 – Test-Retest Results of Helping Ability Item**

Participant	Initial helping 1/Initial helping 2	Retest helping 1/helping 2
1	4/4	4/4
2	4/2	4/3
3	4/4	4/3
4	0/3	4/3
5	2/2	2/3

There is some evidence of construct validity between the helping item (HI) and the Social Ability Scale (SAS) (Table 17). Spearman's rank correlation coefficient indicated a coefficient of .477 ( $p < .01$ ) between the total score of the HI and the SAS. Analyzing the statements separately, it was found that helping statement 2 has a higher correlation of .539 ( $p < .01$ ) with SAS and helping statement 1 was not significantly correlated with the SAS.

Spearman's rank correlation coefficient between the helping ability statements was .55 ( $p < .01$ ). In terms of individual SAS items and the helping ability item and statements, a significant relationship was found between the SAS item "response to

name”, helping statement 2 and the total score of HI ( $p < .01$ ). Helping statement 2 and the total score of the HI were also significantly associated with the ability to make verbal responses. Generally speaking, the higher the score on the HI, the higher the score on the SAS. Participants who scored the 7 or 8 out of a possible score of 8 on the HI ( $n=20$ ) had a SAS range of 21 to 26. Similarly, participants who scored 6 or 5 on the HI ( $n=10$ ) had a SAS of 12 to 26. Participants who scored 4 or 3 ( $n=5$ ) had a range of scored from 18 to 25.

#### **4.5 Frequency Distributions: Cognitive Limitations, Social Ability and Helping Ability**

##### **4.5.1 Dementia Rating Scale**

Table 13 provides information on the Dementia Rating Scale and subscales. In particular Cronbach’s alpha is reported and indicates good internal consistency for the total DRS ( $\alpha = .91$ ) and except for the initiation and perseveration subscale, there is reasonably good internal consistency for the subscales. The cut-off scores for total DRS (Fama et al., 1989, Salmon et al., 1989) and the subscales (Goldstein et al., 1997) are included and indicate that some participants would be assessed as not having cognitive limitations. Sixty percent of participants scored above the cut-off score for cognitive limitations for attention and construction. Such findings speak to the need for tools that discriminate progression stage and to the variability that occurs in the day to day functioning of individuals with a progressive dementia. Because this research does not have a gold standard to compare the DRS, it is impossible to speculate on whether or not participants may have been assessed correctly for cognitive limitations. The small number

of participants who score above the cut-off for memory likely indicates that memory deficits occur early on in the progression of dementia.

In table 13, the average scores are indicated and also the range and standard deviation. For the total DRS and subscales, the range is quite wide. Coblenz (1973) as cited in Mattis (1988) reported from a study of 30 “demented patients,” an average score of 79.55 with a standard deviation of 33.98. Correspondingly, the mean scores for “attention” was 23.55, “initiation and perseveration” was 21.37, “construction” was 2.55, “conceptualization” was 21.18 and “memory” was 10.91. In a more recent study examining the norms of neuropsychological tests, 73 patients with dementia were compared with psycho-geriatric patients with psychiatric problems but not dementia. The average scores from those with dementia were 87.03 for the total DRS, 29.95 for attention, 20.30 for initiation and perseveration, 23.18 for conceptualization, 3.37 for construction and 10.03 for memory subscales (Marcopulos et al., 1999). Overall, frequencies for the total DRS from this research are comparable with previous reports. Participants in this research scored somewhat higher in attention and construction, markedly worse in initiation and perseveration, and somewhat worse in memory subscales.

Previous studies have reported a direct association between education and the scores on the DRS and an inverse association between age and scores on the DRS (Bennet et al., 1997, Lucas et al., 1998) . However for this research, the Spearman’s correlation coefficient ( $\rho$ ) did not indicate a significant relationship between age and education and the scores on the DRS. Previous studies have also noted the complex

relationship between depression and dementia but Table 13 indicates a lack of association between the DRS and the facial affect recognition item with the several measures of depression.

**Table 13 – Dementia Rating Scale/Subscale – Cut-Offs for Scale and Subscales, Frequency Above Cut-Offs, Averages, Range and Standard Deviations**

<b>Dementia Rating Scale – Cutoffs for Scale and Subscales, frequency above cutoffs, averages, range and Standard Deviations</b>						
<b>n = 35</b>						
Scale/Subscale	Cut-offs for probable dementia and impairment in subscales	n = participants who scored above cutoffs	%	Average Score amongst all Participants	Range	SD
Total DRS Alpha=.91	123/144	3	8.6	79.9	9-125	26.82
Attention Alpha=.84	32/37	21	60	30.31	7-37	7.68
I/P Alpha=.58	29/37	4	11.5	15.37	2-35	15.37
Construction Alpha=.88	4/6	21	60	4.4	0-6	2.1
Conceptualization Alpha=.72	32/39	4	11.5	21.4	0-37	8.3
Memory Alpha=.73	19/25	2	6	8.17	0-24	5.4

#### **4.5.2 Facial Affect Recognition Item**

Participants' ability to recognize facial expression was examined using an item in the Abilities Assessment Inventory (Dawson et al., 1993). In the item, participants were shown 3 pictures of a person expressing different emotions and asked to choose "happy, sad or angry" to describe the person's face. The majority of research participants (71.4%, n=25) scored 3 by correctly identifying all 3 faces. A total of 17.1% (n=6) attained a

score of 2, 8.6% (n=3) a score of 1 and 2.9 % (n=1) a score of 0. The facial expression that the participants had the most difficulty recognizing was anger. Ten participants could not accurately identify the facial expressions. Five of these ten participants had problems identifying the facial expression of anger alone and one mixed the facial expressions of sadness and anger. Only one participant had difficulty identifying sadness alone and two participants identified anger but not sadness or happiness. One participant remarked, "What do you think I am, a psychiatrist, I can't tell what this person is feeling".

During data collection, it seemed that some participants were having difficulty following instructions, that is they seemed to understand that the request to "name the face" but they could not understand the instructions of choosing one of three options. For example, a few participants identified that the angry face was "upset." The participant that misidentified sadness still applied a negative emotion by saying, "That boy is sulking." Other participants responded to the angry expression picture by replying, "I don't know." For this research, the ability to recognize facial expression was significantly correlated with the DRS and all but the "conceptualization" subscale (Table 14). In particular, it may be that remembering to select from a list of descriptors taxed participants' attention and memory. It was not simply facial affect recognition that was being measured; it was also the ability to pay attention and remember and select from the choices. For future research, it might be more appropriate to ask individuals with a progressive dementia to describe the facial expression in their own words.

**Table 14 - The Relationship Between Facial Affect and DRS and Subscales**

	DRS	Attention	I/P	Construction	Conceptualization	Memory
Facial Affect	.496**	.338*	.499**	.521**	.333	.671**

\*Correlation is significant at the .05 level (2-tailed significance)

\*\*Correlation is significant at the .01 level (2-tailed significance)

#### **4.5.3 Social Abilities**

For this research, the average score of the SAS was 23.5/26 (standard deviation of 3.06) with a range of 12 to 26. This average score was higher than that previously reported by Rivera (1998) in her study of 30 cognitively impaired woman. Women in Rivera's (1998) study had an average score of 22.0 for 28 items (subsequent to her analysis, one of the items was removed from the scale).

Wells and Dawson (2000) devised categories of high, moderate and low scores for the SAS that are expressed in percentages (Table 15). They categorize the SAS and the specific abilities of attention, humour and conversation in the SAS as high (having scores of over 75%), moderate (scores between 50% and 75%) and low ability (scoring under 50%). Following this categorization, it is apparent that most of the participants (n=31, 91%) demonstrated high scores in social abilities (total SAS).

**Table 15 - Participants' High, Moderate and Low Scores on the SAS**

Participants Scores on the SAS	>75% High		50-75% Moderate		<50% Low	
	n =	%	n =	%	n =	%
Attention	33	94.0	1	1.0	3	1.0
Conversation	29	82.0	3	3.0	8.5	3.0
Humour	27	77.0	6	6.0	5.7	2.0
Total Social Ability	31	91.0	2	2.0	3	1.0
Helping 1	18	51.4	14	40.0	3	8.6
Helping 2	18	51.4	17	48.6	Non	Non
Helping Item Total	20	57.1	13	37.2	2	5.7

Further analysis of SAS items was conducted. Identifying the number and percentage of participants who scored 100% provides information on tasks that were more likely to be successfully completed by most participants (Table 16). The item in the SAS that had the lowest successful completion was the item in which the participant was specifically observed for her response to the interviewer stating her name. A 100% was scored if the participant responded to the interviewer by stating her name or by repeating the name of the interviewer. For this item 40% (n=14) of the participants scored 100%. The other 60% responded by smiling with no repetition of name. For another item, the ability to stay on topic in a conversation, 77% (n=27) of participants attained a 100% score. The other 23% (n=8) of participants did not stay on topic during their interview with the investigator. However, these 8 participants maintained interaction with the investigator by listening, nodding and making distinct verbal responses. For the other items, more than 80% of participants achieved 100%. Overall, participants seemed to demonstrate high level social abilities as measured by the SAS items.

**Table 16 – Participants’ Scoring 100% on Items in the SAS and Helping Ability**

Items	n =	%
Greetings	33	94.3
How are you	32	91.4
Response to name	14	40.0
Handshake	34	97.1
Engage and stay on topic	27	77.1
Engage and verbal response	29	82.9
Nonverbal response	33	94.3
Listening	28	80.0
Humour-cartoon	28	80.0
Humour Joke	25	71.4
Helping 1	18	51.4
Helping 2	18	51.4
Helping Item	14	40.0

#### **4.5.4 Helping Ability**

Table 16 indicates that similar to SAS item scores, many of the participants demonstrated successful completion of helping ability items. Approximately half (51%; n=18) scored 4 of a possible 4 for their response to helping ability statement 1 meaning that they asked for elaboration or asked why the investigator was sad. Two participants responded to the helping statement 1 (“I am sad”) by asking “What am I supposed to say to that?” and “Is this part of the questions I need to answer?” These responses were given a score of 4. Almost one-quarter of participants (22.9%; n=8) scored 3 by providing a verbal response suggesting empathy such as “that’s too bad”, 17.1% (n=6) provided a verbal response and 8.6% (n=3) did not respond.

In comparing helping statement 1 and helping statement 2 (Table 15), all of the participants on helping statements 2 (“I am sad because a cat I had for 20 years died last night”) provided some type of verbal indication of sympathy. Some examples included



the following responses: “it’s very sad when a pet dies”, “they are part of your family” and “we owned dogs when I was young and it was always sad to see them go”. Other responses that were given a full score were, “there is no use in being sad, it is a waste of time, pets die” or “you look unhappy, I think you need a haircut it will make you feel better.”

## **4.6 Research Questions**

### **4.6.1 Research Question 1**

Research question 1 asked “What is the relationship between the cognitive limitations and social ability?” and more specifically,

- 1.a) What is the relationship between cognitive limitations as measured by the Dementia Rating Scale (DRS) and social ability as measured by the Social Abilities Scale (SAS)?

The relationship between participant’s cognitive limitations (DRS) and social abilities (SAS) was examined using Spearman’s rank correlation coefficient ( $\rho$ ) (Table 17). The relationship between the DRS and the SAS was statistically significant (.64,  $p < .01$ ). Although there was some variability in SAS scores among participants who scored low in the DRS, a scatter graph confirmed the direct relationship between the DRS scores and the SAS scores. The relationship between the DRS subscales and the SAS items ranged from .463 - .662 ( $p < .01$ ) (Table 17).

Specific items of the SAS were more highly associated with the DRS and the subscales. These items were: ability to engage and stay on topic, ability to engage and verbal response, and the response to the cartoon were the items that were significantly

related to the DRS total and to all of the subscales. The SAS had the highest correlation with the conceptualization and memory subscales of the DRS. As indicated in Table 17, the relationship between the DRS and SAS is direct, meaning that the greater the cognitive limitations the lower the social ability.

1.b) What is the relationship between cognitive limitations as measured by the facial affect recognition item (FA) of the Abilities Assessment Inventory and social ability as measured by the Social Abilities Scale (SAS)?

Using Spearman's rank correlation coefficient test, the relationship between the SAS and the FA was .429 ( $p < .05$ ). SAS scores varied in relation to scores on the FA. For participants who scored 3 ( $n=25$ ) on the FA, there was a range of scores on the SAS of 18-26. Participants who scored 2 ( $n=6$ ) had a range of scores from 20-25, on the SAS. Participants who scored 1 ( $n=3$ ) had a range from 12-26 and the participant who scored 0 had a score of 20. Further analysis was done to determine relationships between SAS and FA item (see Table 17). Listening and nonverbal response had the highest correlation with the abilities involved in recognizing and naming faces. The relationship between FA and SAS was direct and the same as research question 1a) and indicates that the greater the cognitive limitations, the lower the social ability.

**Table 17 - The relationship between HI, helping statements, FA, DRS, and subscales and items of the SAS and SAS**

	Greetings	How are you	Response to name	Handshake	Engage and stay on topic	Engage and verbal response	Non-Verbal response	Listening	Humour Cartoon	Humour joke	Total Social abilities
<i>Helping 1</i>	.209	.143	.304	.083	.396*	.354*	.212	.138	.417	-.222	.309
<i>Helping 2</i>	.317	.079	.562**	.142	.212	.446**	.204	.162	.243	.250	.539**
<i>Helping total</i>	.146	.137	.487**	.544	.346 *	.432**	.213	.151	.387*	.013	.477**
<i>Facial Affect</i>	.162	.265	.138	.321	.356*	.075	.461**	.517**	.355*	.057	.429*
<i>DRS total</i>	.272	.180	.410*	.289	.471**	.502**	.402*	.350*	.449**	.196	.644**
<i>Attention</i>	.274	.242	.189	.291	.474**	.429*	.405*	.200	.472**	.119	.479**
<i>I/P</i>	.231	.268	.318	.289	.440**	.430**	.403	.244	.473**	.116	.531**
<i>Conceptualization</i>	.195	.217	.478**	.281	.551**	.360*	.403*	.468**	.355*	.157	.662**
<i>Construction</i>	.381*	.126	.325	.290	.247	.471**	.404*	.355*	.443**	.163	.463**
<i>Memory</i>	.258	.120	.167	.306	.435**	.353**	.440**	.240	.455**	.129	.550**

\* Correlation is significant at the .05 level (2-tailed significance)

\*\* Correlation is significant at the .01 level (2-tailed significance)

#### 4.6.2 Research Question 2

Research Question 2 asked, "What is the relationship between the cognitive limitations and helping ability?" and more specifically,

2. a) What is the relationship between cognitive limitations as measured by the Dementia Rating Scale (DRS) and helping ability as measured by the helping item (HI)?

A Spearman rank correlation coefficient ( $\rho$ ) was used to analyze the relationship between the DRS and the HI as well as the two helping statements (1 and 2). Table 17 describes the results. There was a significant correlation coefficient between the DRS and the HI ( $p < .01$ ) and between DRS and helping statements 1 ( $p < .05$ ) and 2 ( $p < .01$ ). There

were significant relationships between the DRS subscales and HI. The HI had the highest correlation with the DRS subscales of conceptualization and memory. The relationship between the DRS and HI was direct, indicating that the greater the cognitive limitations the lower the helping ability.

2.b) What is the relationship between cognitive limitation as measured by the facial affect recognition item of the Abilities Assessment Inventory and helping ability as measured by the helping item (HI)?

A Spearman rank correlation coefficient ( $\rho$ ) was used to analyze the relationship between the FA and the HI as well as the helping statements. There was no significant relationship noted between facial affect (FA) and the HI.

#### **4.7 Summary**

In terms of the two research questions, findings indicate an association between cognitive limitations as measured by the DRS and social ability (SAS) and helping ability (HI) among female residents with a progressive dementia living in long-term care facilities. But for FA as a measure of cognitive limitations, there is less consistency. Facial affect recognition (FA) was associated with social ability (SAS) but not helping ability (HI). However, within the 35 participants, there was much variation and some participants who were identified as having severe cognition limitations also demonstrated high social and helping abilities.

Generally speaking, more participants scored high on social abilities (SAS) compared with helping abilities (HI). This is likely related to its demands, that is, the SAS

items measure “response to” as opposed to “initiation of” social interaction. The SAS is a more established tool but has still not been widely tested. Compared with social ability, helping ability of individuals with a progressive dementia has been addressed less often in the literature. In attempting to develop two items (physical and verbal helping), one item, the physical-helping item, had to be abandoned soon into data collection. The verbal-helping item (HI), and perhaps more so, the helping statement 2 with its concrete reference to the reason for sadness, may be useful for other future studies.

The DRS is a well-established tool that seemed to perform as expected. Participants’ scores on the memory subscale indicated deficits that would be expected given the inclusion criteria for this research. The FA has not been widely tested and the full extent of what is being measured by this tool is open for discussion. The tool required that participants not only correctly identify emotions from a picture, a difficult task in itself, but also that they attend to and remember specifics instructions that offer a choice of answers. This is a highly complex task that involves more than recognition.

Chapter 5 discusses how these findings relate to the Disablement Model and the implications for theory, practice, quality of life issues and for policy development.

## **CHAPTER 5**

### **Discussion**

Chapter 5 consists of six sections and presents a discussion of research findings in relation to the conceptual model (Disablement Model), theory and practice implications, quality of life in long-term care facilities, policy development and education, limitations and suggestions for future research.

#### **5.1 Disablement Model**

Jette's (1997) Disablement Model posits that the disease process leads to impairment, limitations and disability. The model was designed to assist in analyzing factors that affect the disablement process and that are amenable to rehabilitative interventions (Jette, 1997). The research and research questions were framed within this model but did not make use of the entire model. In particular, the relationship between limitations and ability were examined. Cognitive limitations as measured by the Dementia Rating Scale (DRS) and the facial affect recognition item (FA) were examined in relation to social ability as measured by the Social Abilities Subscale (SAS) and helping ability as measured by the helping item (HI).

The Model (Figure 1) also includes factors that could affect the disablement process including risk, extra-individual and intra-individual factors. These factors were not addressed in the research questions. There seem to be no models that specifically address cognition and social ability. On the whole, the Model served well to guide the research and assist in stating the research questions.

## **5.2 Theory and Practice Implications**

The implications for theory and clinical practice are described for each research question.

### **5.2.1 Research Question 1: “What is relationship between cognitive limitations and social ability?”**

The findings demonstrated a significant and direct relationship between cognitive limitations as measured by the DRS and FA and social ability as measured by the SAS. The greater the cognitive limitations, the lower the social ability. However, it was also clear that the 35 research participants scored high in terms of the SAS and did fairly well on the FA. At an individual level, some participants who had severe cognitive limitations demonstrated appropriate responses in relation to social ability.

Although there are few studies, the relationship between cognitive limitations and social ability has been demonstrated. Baum et al. (1993) found a significant relationship ( $r=.77$ ) between problem solving ability and social interaction ability. Rivera (1998) found that there was a significant difference in social abilities between cognitively intact and cognitively impaired women using the Mini Mental Status Exam to measure cognition. It is not surprising that, in general, individuals with a progressive dementia display lower levels of social ability. Changes in cognition and in particular, changes in memory would be expected to have an impact on social interaction. However, the ability to engage socially varies and some individuals with a progressive dementia have social

abilities that are fairly well expressed.

Evidence from this research and other studies on individuals with a progressive dementia that have used the SAS (Rivera, 1998, Wells & Dawson, 2000) report higher social ability scores than might be expected. For some time, clinicians have remarked anecdotally about individuals with a progressive dementia who demonstrate considerable social ability. But little has been done to quantify social ability especially in comparison to other efforts such as those to quantify cognitive limitations. Several tools exist that measure cognitive functioning and limitations.

SAS scores provide a global measure of social ability but do not provide specific information. "Average" scores are not clinically useful except to create awareness of trends and ranges of ability that might be appreciated at an individual level. Cumulative scores, whether related to cognitive limitations or social ability, do little to inform clinicians about an individual's specific strengths and deficits.

Individual scale items that relate to aspects of cognition or social ability such as memory or attention are much more useful for clinical assessment and intervention. For some of the SAS items, it was found that most participants achieved 100%. These items were the ability to respond appropriately and greet a person when they say "hello" and "how are you?" and to respond to an outstretched hand by shaking the person's hand. These items require attention but not initiation. The joke item ("kangaroo in a bar") likely posed some difficulty for participants because it required attention and memory. A shorter



worded joke might have lead to participants having a higher success rate.

Clinically, it is useful to identify specific types of abilities that may be associated with a progressive dementia. In this research, the social abilities that were specifically associated with the cognition were the abilities: to engage and stay on topic, to engage and provide a verbal response, to engage and provide a nonverbal response and listening, to state one's own name and to respond to the cartoon (even if they did not think it was funny).

A skill that is not included in the SAS is the ability to initiate social interaction. Baum et al. (1993) identified from focus groups with families that this skill was important to family members when interacting with a relative with a progressive dementia. Baum et al. (1993) suggested that the ability to initiate social interaction with familiar others is maintained even in the moderate stage of dementia. The ability to initiate social interaction would be dependent on opportunity and context and would be difficult to observe systematically both in research and in clinical practice.

An assumption for this research was that mood or conditions such as depression would affect social ability and this might be especially true for the ability to initiate social interaction. The literature on long-term care suggests high levels of depressive symptoms and unhappiness among residents. In this research, there were no relationships between social ability and the several measures used to measure depression. The 5-item Geriatric Depression Scale was selected for its brevity and simplicity but at least 1 of the items may

have not fit the long-term care context (“Do you prefer to stay in your room rather than going out?”).

Findings suggest that cognitive limitations in conceptualization and memory are highly related to social ability. The ability to conceptualize is lost before language is lost, however little is known about how limitations in conceptualization affect communication ability (Knuf, 2000). Memory deficits likely affect the communication abilities of individuals with a progressive dementia because of problems in remembering words or “word finding”. Again, it is useful for clinicians to know the area of deficit to plan communication strategies for obtaining information and engaging with individuals with a progressive dementia.

Although there was a significant and direct relationship between of facial affect recognition and social ability, participants seemed to have some difficulty with the way data were collected. Specifically, the use of pictures to denote facial expression and the selection of (“happy, sad or angry”) may have added complexity to the task. As noted earlier, the administering the FA meant that participants had to perform several tasks including view the picture, attend to instructions, remember the three choices and make a selection that matched the picture. The FA seems to go beyond simple facial affect recognition and requires attention, memory and responding to choice. An alternative approach and one that might better capture facial affect recognition could be to show the picture and ask participants to describe what the person in the picture is doing or feeling.

Research by Albert et al. (1991) suggested that individuals with a progressive dementia can accurately read facial expression but lack the ability to communicate a description of the expression. Clearly, more work is required in the measurement of facial affect recognition and the importance of this ability for social interaction by individuals with a progressive dementia needs further exploration.

In summary, the implications for theory and practice for research question 1 involve several measurement and clinical practice issues. From a theoretical perspective, more work on the constructs of social ability and facial affect recognition is needed. The measurement of these constructs must take into account not only the development of items that can measure a range of abilities but the way in which data are collected in order to accurately measure these abilities. From a clinical practice perspective, more research could enhance social ability assessment and subsequent intervention and intervention studies could guide the development of communication strategies for clinicians who are working with individuals with a progressive dementia.

#### **5.2.2 Research Question 2: “What is relationship between cognitive limitations and helping ability?”**

Findings were inconsistent regarding this research question. The findings demonstrated a significant and direct relationship between cognitive limitations as measured by the DRS and helping ability as measured by the HI. However, there was no relationship between cognitive limitations as measured by the FA and helping ability as

measured by the HI.

There are no studies that directly examine the relationship between cognitive limitations and helping ability among individuals with a progressive dementia although some studies report instances of helping behaviour ( Mayhew et al., 2000, Sabat & Collins, 1999). For example, Sandman et al. (1988) reported that when 5 individuals with a dementia were left alone at mealtime, those who had the most cognitive ability helped others that were less cognitively able.

Although the findings indicate that the greater the cognitive limitations, the lower the helping ability, still the existence of helping ability was observed during the course of data collection. There are no established items to measure helping ability and it is a challenge to develop items that fit with the long-term care environmental and social context. Helping ability might more accurately and comprehensively be measured through intensive observation protocols but this is not often a feasible option in research or clinical practice.

For this research, two items were initially developed: the verbal helping item and the physical-helping item. Early in data collection, it became clear that the physical-helping item was confounded by participants' possible sensory deficits (vision and hearing). Other chronic conditions that restrict mobility or response time might also confound the physical-helping item. These concerns speak to the difficulty of developing items to measure helping ability within the context of long-term care.

The verbal-helping item consisted of two statements. Helping statement 1 was non-specific ("I am sad.") compared with helping statement 2 that was anchored in a specific sad event ("I am sad because a cat I had for 20 years died last night."). There is some evidence to suggest that participants were more responsive in their comments to the "anchored" sadness. However, even this item must be carefully considered. A sympathetic response may rest more on positive feelings about pets or cats and a less expressive response on the contrary, may rest on negative feelings about pets or cats. Similar to earlier discussion, there may also be a communication problem that inhibits the expression of positive or negative responses. It is possible that participants who responded sympathetically, did so because of socially prescribed norms. However, it could be argued that responses based on social norms might require higher levels of judgment, insight and memory than possessed by most individuals with a progressive dementia.

It is difficult to speculate why the FA was not significantly associated with HI. As indicated earlier, although participants did fairly well, the FA requires a complex set of tasks and perhaps this was a factor. The SAS and HI were correlated and both were correlated with the memory subscale of the DRS. Perhaps helping ability is a type of social ability that requires more expression and is more difficult to capture in an item or in this case, a two statement item.

In summary, the implications for theory and practice for research question 2

involve some measurement and clinical practice issues. From a theoretical perspective, much more needs to be done to refine and measure the construct of helping ability. From a clinical practice perspective, there seems to be little recognition or information about helping ability of individuals with a progressive dementia. This may be partially related to the mandate of health care providers in long-term care facilities and that is to provide help and care to individuals with a progressive dementia and not to explore, develop and support their helping ability.

### **5.3 Social Ability, Helping Ability and Quality of Life**

Kitwood (1997) identified that quality of care depends on having a clear and accurate understanding of a person's abilities, tastes, interests and values. Kitwood (1997) stipulated that the extent of the social disability displayed by people with dementia is related to their quality of care and quality of life and individuals with dementia have a need to give. From a clinical perspective, identifying the need to be helpful and supporting it through interventions is linked with quality of life in long-term care.

Acton et al. (1999) reported that individuals with dementia communicated that helping and caring others were important to their meaning of life. Quality of life outcomes for people living under these circumstances entail "opportunities to socialize, to engage in activities and to achieve a sense of social integration" (Bamford & Bruce 2000, p. 544).

For this research, quality of life was not measured. However, it would be

appropriate to include this measure in future research that examines cognition, social ability and helping ability.

#### **5.4 Implications for Policy Development and Education**

The Disablement Model (Jette, 1997) provides a basis for rehabilitation interventions to assist individuals to reach and maintain their highest levels of skill and function. Although designed to address the physical aspects of disease, impairment, limitations and disability, the Model has been used here as a framework to examine cognitive limitations and social ability. Findings from this research fit the Model and it is not surprising that greater cognitive limitations are related to lower social ability. But the Model also serves to guide interventions and this idea might be extended to include interventions to assist individuals with a progressive dementia to reach and maintain their social ability.

Policy development based on the Model would address social and physical environment interventions designed to support “ability” among individuals with a progressive dementia. An initial step would seem to be the development of policies to address the educational needs of health care providers in relation to cognition, social ability and helping ability. Further to this step is the need to develop policies that identify social ability assessment as “basic” assessment along with the current emphasis on assessment of cognition and activities of daily living (ADL). Dawson et al., (1993) have done some preliminary work on the assessment of abilities (“Enablement Model”) and

some of this work might be integrated into the Model (Jette, 1997).

In order to be effective clinically, policies must be transferred into procedures. Examples of procedures include annual education sessions to long-term care staff on promoting maximum ability of individuals with dementia, and 6 month ability assessment protocols for all residents. Family caregiver programs might be developed to educate family and friends about social ability and how to enhance social ability. A team of health care providers could work with family members in long-term care as well as in the community as soon as possible after a diagnosis of probable dementia.

Education of health care providers and family members is important. Education of future health care providers is also important. Nursing students and students in other health care provider groups should be made aware of the "ability" as well as the "disability" of individuals with a progressive dementia. Social ability assessment should be part of the multidimensional assessment of older adults that forms course content in nursing programs and programs of other health care providers.

### **5.5 Limitations of the Study**

This research has some limitations. First, the 35 participants were not randomly selected and although comparisons were made with the Manitoba population, the findings cannot be said to be broadly generalizable. The 35 participants were all women with family members who could provide consent. The participants were screened by facility staff who made have exercised selection criteria beyond the established inclusion criteria. Some family members who declined to consent said that their relative tended to be



suspicious or difficult.

Second, the research was cross-sectional. The relationship between cognitive limitations and social ability and helping ability was examined at one point in time. It is not possible to make conclusions regarding “change” in the relationship. Longitudinal research would provide a better understanding of the relationship between cognitive limitations and social ability and helping ability.

Third, the research did not take into account all of the factors that might affect the relationship between cognition and ability. The Model identifies several factors associated with the disablement process. This research examined some of the pertinent sociodemographic (age and education) and health (depression) factors.

Another limitation is statistically based. The more statistical analyses, the more likely that results occur by chance. When statistical significance is set at minimum of .05, this means that the probability of a type 1 error (that is finding a relationship that is not a true relationship) occurs 5 times out of 100 analyses. It is impossible to speculate whether or not any of the major findings were “chance” findings.

## **5.6 Future Research**

Given the limited research on cognition, social ability and helping ability and the demographics of aging and cognitive change, it seems reasonable to suggest that more research be conducted on cognition and ability. In particular, research should emphasize cognition, social ability and helping ability in relation to:

1. quality of life in long-term care;
2. assessment/measurement of social ability and helping ability;
3. facial affect recognition;
4. interventions such as communication strategies;
5. policy and procedure development in long-term care; and
6. education programs for family caregivers.

From a theoretical perspective, more work should be directed to the development of the Disablement Model (Jette, 1997) or variants of the model to further enhance our understanding of cognitive limitations and ability.

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ID# \_\_\_\_\_

Unit \_\_\_\_\_

Date \_\_\_\_\_

Demographic Data Sheet

Date of Birth: \_\_\_\_\_

Marital Status:

Married 1

Single 2

Divorced 3

Separated 4

Widowed 5

Family Status:

Children 1

Other close relative (named as next of kin in chart) 0

Education: \_\_\_\_\_

Ethnicity: \_\_\_\_\_

Religion: \_\_\_\_\_

Date of admission: \_\_\_\_\_

Medical Diagnosis (name top 6 diagnosis- including diagnosis related to dementia)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Medications (current)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Activities of Daily Living and Difficult Behaviour:**

**Hygiene :**

Dressing: Independent with or without assistance devices  
Assistance required

Bathing: Independent with or without assistive devices  
Assistance required

Toileting: (Urine (a))

Continent at all times  
Occasionally incontinent  
Always incontinent

Independent with toileting  
Requires assistance

(Bowels)

Continent at all times  
Occasionally incontinent  
Always incontinent  
Independent with toileting  
Requires assistance with toileting

**Mobilizing:**

Independent with/without assistive devices  
Assistance required

(Transfers)

Independent  
Assistance required, specify

**Eating:** Independent  
Requires minimal assistance (food cut up)

**Difficult Behaviour:**

No problems indicated  
Occasional problems

**Identify Type of Behaviour:**

Wandering, pacing  
Verbal aggression  
Resistance to care  
No behaviours

*Appendix B*

**Five Item Geriatric Depression Scale**

1. Are you basically satisfied with your life? Yes\_\_No\_\_
2. Do you often get bored? Yes\_\_No\_\_
3. Do you often feel helpless? Yes\_\_No\_\_
4. Do you prefer to stay in your room rather than going out? Yes\_\_No\_\_
5. Do you feel pretty worthless the way you are now? Yes\_\_No\_\_

**Single Self Rated Depression Item**

Do you often feel sad or depressed? Yes\_\_ No\_\_

**Attention****A. Digit Span**

**I'm going to say some numbers and when I'm through I want you to repeat the numbers in the same order ... Say them just the same way I did**

- A1. Forward      **25**  
                      **316**  
                      **4792**

(0, 2, 3, 4)      \_\_\_\_\_

**Now when I say some numbers I want you to say them backward...**

**For example, if I said 1-2, you would say 2-1... Understand?... Ready?**

- A2. Backward      **14**  
                      **539**  
                      **8593**

(0, 2, 3, 4)      \_\_\_\_\_

Score A \_\_\_\_\_

(0-8)

**B. Two Successive Commands**

**I'm going to give you some commands... Do what I say and then relax.**

- B1. "Open your mouth and close your eyes" (1pt) \_\_\_\_\_

- B2. "Stick out your tongue and raise your hand" (1pt) \_\_\_\_\_

Score B \_\_\_\_\_

(0-2)

<p>IF SCORE B = 2, GO TO E ENTER MAX SCORE FOR C-D</p>
--

**C. Single Command**

**I'm going to give you some commands... Do what I say then relax.**

- C1. "Open your mouth" (1pt) \_\_\_\_\_

- C2. "Stick out your tongue" (1pt) \_\_\_\_\_

- C3. "Close your eyes" (1pt) \_\_\_\_\_

- C4. "Raise your hand" (1pt) \_\_\_\_\_

Score C \_\_\_\_\_

(0-4)

**D. Imitation**

**Watch me... Do what I do... Imitate what I'm doing... Do this.**

- D1. Open mouth (1pt) \_\_\_\_\_

- D2. Stick out tongue (1pt) \_\_\_\_\_

- D3. Close eyes (1pt) \_\_\_\_\_

- D4. Raise your hand (1pt) \_\_\_\_\_

Score D \_\_\_\_\_

(0-4)

## Initiation and Perseveration

### E. Complex Verbal Initiation/Perseveration

**I'd like you to name all the things you can find or buy in a supermarket... You have 1 minute to name as many different items as fast as you can. (60-second time limit, 1 point for each different item)**

1 \_\_\_\_\_  
2 \_\_\_\_\_  
3 \_\_\_\_\_  
4 \_\_\_\_\_  
5 \_\_\_\_\_  
6 \_\_\_\_\_  
7 \_\_\_\_\_  
8 \_\_\_\_\_  
9 \_\_\_\_\_  
10 \_\_\_\_\_

11 \_\_\_\_\_  
12 \_\_\_\_\_  
13 \_\_\_\_\_  
14 \_\_\_\_\_  
15 \_\_\_\_\_  
16 \_\_\_\_\_  
17 \_\_\_\_\_  
18 \_\_\_\_\_  
19 \_\_\_\_\_  
20 \_\_\_\_\_

Score E \_\_\_\_\_  
(0-20)

IF SCORE E > 13, GO TO 1  
ENTER MAX SCORE FOR F-H

### F. Simple Verbal Initiation/Perseveration

**Look at me... Look at what I'm wearing... I'd like you to name all of the things I'm wearing. (60-second time limit, 1 point for each different item)**

1 \_\_\_\_\_  
2 \_\_\_\_\_  
3 \_\_\_\_\_  
4 \_\_\_\_\_

5 \_\_\_\_\_  
6 \_\_\_\_\_  
7 \_\_\_\_\_  
8 \_\_\_\_\_

Score F \_\_\_\_\_  
(0-8)

G. Consonant Perseveration

**Say "bee"... Say "key"... Say "gee"... Now say "bee-key-gee" four times.**

"bee-key-gee"- four repetitions (1pt)\_\_\_\_\_

Score G \_\_\_\_\_  
(0-1)

H. Vowel Perseveration

**Say "bee"... Say "bah"... Say "boh"... Now say "bee-bah-boh" four times.**

"bee-bah-boh"- four repetitions (1pt)\_\_\_\_\_

Score H \_\_\_\_\_  
(0-1)

I. Double Alternating Movements

**Watch me... Do what I'm doing... Do this... Palm up, palm down, now switch... Keep doing it until I tell you to stop.**

palm up/palm down-five repetitions (1pt)\_\_\_\_\_

Score I \_\_\_\_\_  
(0-1)

IF SCORE I = 1, GO TO L ENTER MAX SCORE FOR J-K
--

J. Double Alternating Movements

**Now do this... Fist, fingers out, switch... Keep doing it until I tell you to stop.**

clenched/extended-five repetitions (1pt)\_\_\_\_\_

Score J \_\_\_\_\_  
(0-1)

K. Alternate Tapping

**Now do this... Tap left, then right, then left, then right... Just like this...Keep doing it until I tell you to stop.**

tap left/tap right-ten repetitions (1pt)\_\_\_\_\_

Score K \_\_\_\_\_  
(0-1)

L. Graphomotor Design 1

**Present Card 1 in stimulus booklet. Give sheet of paper to subject. Copy this entire design** (point to entire "ramparts" design from left to right).

**Start right here** (point to paper).

reproduction of "ramparts" (1pt)\_\_\_\_\_

Score L \_\_\_\_\_  
(0-1)

IF SCORE L = 1, GO TO P ENTER MAX SCORE FOR M-O
--



M. Graphomotor Design 2

Present Card 2 in stimulus booklet. **Copy this** (point to circle). **Put it here** (point to paper).  
reproduction of "circle" (1pt)\_\_\_\_\_

Score M\_\_\_\_\_ (0-1)

N. Graphomotor Design 3

Present Card 3 in stimulus booklet. **Copy this** (point to the "X"). **Put it here** (point to paper).  
reproduction of "X" (1pt)\_\_\_\_\_

Score N\_\_\_\_\_ (0-1)

O. Graphomotor Design 4

Present Card 4 in stimulus booklet. **Copy these** (point to alternating XOXO). **Put them here** (point to paper).  
reproduction of "alternating XOXO" (1pt)\_\_\_\_\_

Score O\_\_\_\_\_ (0-1)

## Construction

P. Construction Design 1

Present Card 5 in stimulus booklet. Turn paper over. **Copy this** reproduction of "vertical lines" (1pt)\_\_\_\_\_

Score P\_\_\_\_\_ (0-1)

Q. Construction Design 2

Present Card 6 in stimulus booklet. **Copy this** (point to diamond in box). **Put it here** (point to paper). reproduction of "diamond in box" (1pt)\_\_\_\_\_

Score Q\_\_\_\_\_ (0-1)

IF SCORE Q = 1, GO TO V ENTER MAX SCORE FOR R-U
--

R. Construction Design 3

Present Card 7 in stimulus booklet. **Copy this** (point to square and diamond). **Put it here** (point to paper). reproduction of "square and diamond" (1pt)\_\_\_\_\_

Score R\_\_\_\_\_ (0-1)

S. Construction Design 4

Present Card 8 in stimulus booklet. **Copy this** (point to diamond). **Put it here** (point to paper). reproduction of "diamond" (1pt)\_\_\_\_\_

Score S\_\_\_\_\_ (0-1)

T. Construction Design 5

Present Card 9 in stimulus booklet. **Copy this** (point to square). **Put it here** (point to paper). reproduction of "square" (1pt)\_\_\_\_\_

Score T\_\_\_\_\_ (0-1)

U. Construction Design 6

**Write your full name here** (point to paper). produces signature (1pt)\_\_\_\_\_

Score U\_\_\_\_\_ (0-1)

## Conceptualization

### V. Identifies and Oddities

Present Cards 10-17 in sequence. **Look at these three designs... Which two are the same?... Which are the most alike?** Return to Card 10 and present Cards 10-17 again. **Look at these three designs... Tell me which one is different from the others... Which one doesn't belong with the others?**

- V1. Card 10 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V2. Card 11 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V3. Card 12 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V4. Card 13 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V5. Card 14 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V6. Card 15 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V7. Card 16 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_  
V8. Card 17 Same (1pt) \_\_\_\_\_ Different (1pt) \_\_\_\_\_

Score V \_\_\_\_\_  
(0-16)

### W. Similarities

**In what way are a \_\_\_\_\_ and a \_\_\_\_\_ alike?... How are they the same?** Record responses.

- W1. apple - banana \_\_\_\_\_ (0-2pt) \_\_\_\_\_  
W2. coat - shirt \_\_\_\_\_ (0-2pt) \_\_\_\_\_  
W3. boat - car \_\_\_\_\_ (0-2pt) \_\_\_\_\_  
W4. table - chair \_\_\_\_\_ (0-2pt) \_\_\_\_\_

Score W \_\_\_\_\_  
(0-8)

IF SCORE W>5, GO TO AA ENTER MAX SCORE FOR X-Z
---

X. Priming Inductive Reasoning

Name three things that people \_\_\_\_\_. How are a \_\_\_\_\_,  
\_\_\_\_\_, and a \_\_\_\_\_ alike, the same? Record subject's  
responses.

X1. eat \_\_\_\_\_  
response \_\_\_\_\_ (1pt) \_\_\_\_\_

X2. wear \_\_\_\_\_  
response \_\_\_\_\_ (1pt) \_\_\_\_\_

X3. ride \_\_\_\_\_  
response \_\_\_\_\_ (1pt) \_\_\_\_\_

Score X \_\_\_\_\_  
(0-3)

Y. Differences

I'm going to name three things... You tell me which one doesn't belong  
with the others, which one is different.

Y1. dog-cat-car (1pt) \_\_\_\_\_

Y2. boy-door-man (1pt) \_\_\_\_\_

Y3. fish-car-train (1pt) \_\_\_\_\_

Score Y \_\_\_\_\_  
(0-3)

Z. Similarities-Multiple Choice

\_\_\_\_\_ and \_\_\_\_\_ ... Are they both \_\_\_\_\_, both  
\_\_\_\_\_, or both \_\_\_\_\_?

Z1. apple-banana  
both fruit (2pt) \_\_\_\_\_  
both green (1pt) \_\_\_\_\_  
both animals (0pt) \_\_\_\_\_

Z2. coat-shirt  
both clothing (2pt) \_\_\_\_\_  
both wool (1pt) \_\_\_\_\_  
both fruit (0pt) \_\_\_\_\_

Z3. boat-car  
both means of transportation (2pt) \_\_\_\_\_  
both move (1pt) \_\_\_\_\_  
both clothing (0pt) \_\_\_\_\_

- Z4. desk-chair  
both furniture (2pt)\_\_\_\_\_  
both wood (1pt)\_\_\_\_\_  
both means of transportation (0pt)\_\_\_\_\_

Score Z\_\_\_\_\_

(0-8)

AA. Verbal Recall-Sentence Reading

Present Card 18 in stimulus booklet. **Read this sentence aloud...**  
**Remember the sentence because I'm going to ask you to repeat it later.**

(Not scored)

AB. Verbal Recall-Sentence Initiation

**Make up a sentence using the words "man" and "car"... Remember this sentence also because I'm going to ask you to repeat it later.**

\_\_\_\_\_(1pt)

Score AB\_\_\_\_\_

(0-1)

## Memory

### AC. Orientation

AC1. Day (1pt)\_\_\_\_\_

AC2. Date (1pt)\_\_\_\_\_

AC3. Month (1pt)\_\_\_\_\_

AC4. Year (1pt)\_\_\_\_\_

AC5. Prime Minister (1pt)\_\_\_\_\_

AC6. Premiere (1pt)\_\_\_\_\_

AC7. Mayor (1pt)\_\_\_\_\_

AC8. Address (1pt)\_\_\_\_\_

AC9. City (1pt)\_\_\_\_\_

Score AC\_\_\_\_\_

(0-9)

### AD. Counting Distraction1

Present Card 19 in stimulus booklet. (Turn card lengthwise). **Point out and count all of the A's.**

Score AD\_\_\_\_\_

(0-6)

### AE. Counting Distraction 2

Present Card 20 in stimulus booklet. **Point out and count all of the A's.**

Score AE\_\_\_\_\_

(0-5)

### AF. Verbal Recall-Reading

**Remember the sentence that you read?... Tell it to me.** Record sentence.

complete sentence (4pt)\_\_\_\_\_

boy (1pt)\_\_\_\_\_

brown

dog

(1pt)\_\_\_\_\_

(1pt)\_\_\_\_\_

Score AF\_\_\_\_\_

(0-4)

### AG. Verbal Recall-Initiation

**Remember the sentence you made up?... Tell it to me.**

complete sentence (3pt)\_\_\_\_\_

man (1pt)\_\_\_\_\_

car (1pt)\_\_\_\_\_

Score AG\_\_\_\_\_

(0-3)

### AH. Verbal Recognition-Presentation

Present Card 21 in stimulus booklet. **Read this list of words aloud four times so that you will remember each word.**

AH1. 1st correct reading (1pt)\_\_\_\_\_

AH2. 2nd correct reading (1pt)\_\_\_\_\_

AH3. 3rd correct reading (1pt)\_\_\_\_\_

AH4. 4th correct reading (1pt)\_\_\_\_\_

Score AH\_\_\_\_\_

(0-4)

AI. Verbal Recognition

**I'm going to show you some words, two at a time... For each pair of words, you pick the one that was on the list you just read.** Present Cards 22-26 in stimulus booklet, one at a time.

- |                                     |                                      |
|-------------------------------------|--------------------------------------|
| AI1. <i>evening-head</i> (1pt)_____ | AI4. <i>machine-night</i> (1pt)_____ |
| AI2. <i>inch-plant</i> (1pt)_____   | AI5. <i>fire-milk</i> (1pt)_____     |
| AI3. <i>land-open</i> (1pt)_____    |                                      |

Score AI \_\_\_\_\_  
(0-5)

AJ. Visual Matching

Present Cards 27 and 28 in stimulus booklet. **The designs on this card (point to Card 28) are exactly the same as the designs on this card (point to Card 27)...** When I point to a design on my card, you point to the same one on your card... Now, which design is the same as this one (point to top left design, from subject's point of view, on Card 27)? Match to three remaining designs in any order. Repeat three times.

- |          |                                    |
|----------|------------------------------------|
| AJ1. 1st | presentation of designs (1pt)_____ |
| AJ2. 2nd | presentation of designs (1pt)_____ |
| AJ3. 3rd | presentation of designs (1pt)_____ |
| AJ4. 4th | presentation of designs (1pt)_____ |

Score AJ \_\_\_\_\_  
(0-4)

AK. Visual Memory

**I'm going to show you some designs, two at a time... For each pair of designs choose the one we have just been working with... Point to the one you have just seen.** Present Cards 29-32 in stimulus booklet, one at a time.

- |                       |                       |
|-----------------------|-----------------------|
| AK1. left (1pt)_____  | AK3. right (1pt)_____ |
| AK2. right (1pt)_____ | AK4. left (1pt)_____  |

Score AK \_\_\_\_\_  
(0-4)

### Facial Affect Recognition

Inform the resident that you would like him/her to tell you how the person in the picture is feeling by the expression on his/her face. Record response. A score of 1 is given for being able to accurately describe the expression on each picture expression (total 3 points). If the resident does not respond to the initial request than the resident is asked to choose if the facial expression indicates if the person is sad, angry or happy ( a score of one for each correct answer, for a total of 3).

	Correct (1)	Incorrect (0)
(i) sad	_____	_____
(ii) angry	_____	_____
(iii) happy	_____	_____

Total possible score is 3



## Social Abilities Component of the Abilities Assessment Instrument

### 1. To give and receive attention

a) Greet person with "hello", "good morning," etc. Response is one of the following:

- i) a verbal reply \_\_\_\_\_(4)
  - ii) smile only \_\_\_\_\_(3)
  - iii) eye contact only \_\_\_\_\_(2)
  - iv) mutters \_\_\_\_\_(1)
  - v) no change in behaviour to suggest response \_\_\_\_\_(0)
- Score \_\_\_\_\_(4)

b) Individual's response to "how are you" is one of the following:

- i) a verbal reply \_\_\_\_\_(3) stays on topic
  - ii) verbal but unclear \_\_\_\_\_(2)
  - iii) nonverbal (eye gaze, nod, smile) \_\_\_\_\_(1)
  - iv) no change in behaviour to suggest response \_\_\_\_\_(0)
- Score \_\_\_\_\_(3)

c) Address individual by name and give your name. Response is one of the following: \_\_\_\_\_(3) takes turns

- i) name repetition (repeats your name) or self introduction \_\_\_\_\_(4)
  - ii) facial response (nods, smiles, looks) \_\_\_\_\_(3)
  - iii) body language response (leans forward) \_\_\_\_\_(2)
  - iv) mumbles \_\_\_\_\_(1)
  - v) no response \_\_\_\_\_(0)
- Score \_\_\_\_\_(4)

d) Initiate a handshake (i.e. offer your hand to the person). Response is one of the following:

- i) grasps offered hand (self-initiated) \_\_\_\_\_(3)

- ii) other initiated (you take his/her hand) \_\_\_\_\_(2)
  - iii) initiates letting go \_\_\_\_\_(1)
  - iv) no response \_\_\_\_\_(0)
- Score \_\_\_\_\_(3)
- Subtotal \_\_\_\_\_(14)

### 2. To engage/participate in conversation

Initiate a topic of conversation with the individual. Response is one form topic and verbal, and any from nonverbal.

#### a) Topic

- stays on topic \_\_\_\_\_(2)
  - relates improbable events \_\_\_\_\_(1)
  - no response to topic \_\_\_\_\_(0)
- Score \_\_\_\_\_(2)

#### b) Verbal

- distinct verbal responses \_\_\_\_\_(2)
  - indistinct verbal response \_\_\_\_\_(1)
  - no verbal response \_\_\_\_\_(0)
- Score \_\_\_\_\_(2)

#### c) Nonverbal

- takes turns \_\_\_\_\_(1)
  - looks, listens or nods \_\_\_\_\_(1)
  - no response \_\_\_\_\_(0)
- Score \_\_\_\_\_(2)
- Subtotal \_\_\_\_\_(6)

### 3. Humour appreciation

a) Inform individual that you have a cartoon you would like to show him. Show the cartoon. Response is one of the following:

- laughs out loud or makes relevant comments \_\_\_\_\_(3)
  - laughs quietly \_\_\_\_\_(2)
  - smiles \_\_\_\_\_(1)
  - no response \_\_\_\_\_(0)
- Score \_\_\_\_\_(3)

b) Inform individual that you have a joke you would like to tell him/her. Tell a short joke that is non-prejudicial and non-controversial. Keep a straight face at the punchline (e.g. A kangaroo walked into a bar and asked the bartender for a beer. The bartender gave the kangaroo a beer and said "That'll be 10 dollars." Later the bartender returned and said "We don't get many kangaroos in here." The kangaroo said "I'm not surprised, at these prices.")

Response is one of the following:

laughs at punchline or makes relevant comments	____(3)
changes facial expression at the punchline	____(2)
unexpected response at the punchline	____(1)
no response	____(0)
Score	____(3)
Subtotal	____(3)

- a) Total score achieved =  
(add subtotals) \_\_\_\_\_
- b) Total possible score = 26
- c) % Score =  $\frac{(a) \times 100}{(b)}$

**Helping Ability Item**

I. Researcher states: I am having a difficult day. I feel very sad.

Responses:

1. Asks for elaboration of the difficulty.

\_\_\_\_\_(4)

2. Verbal response suggesting empathy (that's too bad).

\_\_\_\_\_(3)

3. Verbal responses using utterances such as "Oh"

\_\_\_\_\_(2)

4. Nonverbal response.

\_\_\_\_\_(1)

(i.e., eye contact with facial behaviour demonstrating concern)

5. No response.

\_\_\_\_\_(0)

SUBTOTAL : \_\_\_\_\_/4

Researcher states: A cat my family had for 20 years died last night.

Participant responses:

1. Asks for elaboration or relays a story of a similar nature.

\_\_\_\_\_(4)

2. Verbal response suggesting empathy (that's too bad, oh No)

\_\_\_\_\_(3)

3. Verbal response using utterances

\_\_\_\_\_(2)

4. Nonverbal response.

\_\_\_\_\_(1)

5. No response.

\_\_\_\_\_(0)

Subtotal \_\_\_\_\_/4

Total Score \_\_\_\_\_/8

**Helping Scale (Physical).**

The researcher drops a book in direct view of resident:

Responses:

The resident reaches down to pick up the book and gives it back to the researcher – scores yes for helping behaviour

The resident points or verbally indicates that the researcher has dropped the book – score yes for helping behaviour

No response – score No for helping behaviour

**To the Program Care Managers:**

Thank you for your assistance in this study:

**Cognition, Social Ability, and Helping Behaviours Among Residents with Cognitive Limitations**

This study examines if changes in the ability to remember and sequence tasks (cognitive limitations) affect the person's ability to interact socially. The study involves administering face to face interviews to female residents over 65 who live at Personal Care Homes. This face to face interview lasts about one hour and involves social conversation with the resident and asks questions that measure cognitive changes, depression, social ability and helping behaviour. Information will also be collected from the chart. In order to administer the interviews or to collect information from the chart the family and the participant must agree to participate. Because of the vulnerability of the client the family must show their agreement by signing a consent. If possible written consent will also be attained from the resident.

**Program Manager Involvement :**

Either the Program Manager/ Designate is asked to identify the potential participants and request the responsible family member of a potential participant to consider being contacted by the researcher. The family needs to know that speaking to the researcher about the study does not commit them to signing the consent. The family can decide to withdraw at any time with no consequence to themselves or their relative. Also, if their relative indicates that they are not interested in being involved there will be no attempt to interview her. Once contact with the family member has been made and they have agreed to being contacted one of the above named people provides the researcher the name and phone number of the family members and the name and unit of the participant. The researcher can either phone the researcher or leave a list of names of family and participants at agreed location for the researcher to acquire. At this point it is the researcher's responsibility to contact the family, discuss the research and have a consent signed if the family continue to agree.

Resident Managers will need to notify staff on the unit that a researcher will be collecting information from their residents' and their resident's charts.

**Further Questions:**

You can contact Barbara Tallman directly by phoning, 788-8591 or 261-5968. You can also contact Barbara's thesis supervisor, Dr. Lorna Guse at 474-6220. This research has been approved by the Human Ethics Research Board and The University of Manitoba and the Riverview Research Access Committee. If you have any concerns or complaints regarding a procedure in this study, please contact the Human Ethics Secretariat at 474-7122.

Thank you for your consideration. Barbara Tallman R.N., B.Sc. (Master's of Nursing Candidate)

**Introductory Script Family:**

Hello, my name is (insert research assistants name).

I am a research assistant for a research project being conducted at your \_\_\_\_\_(insert appropriate relationship) residence at (insert name of Long Term Care Institution).

I am phoning to see if you would be interested in signing a consent that permits the researcher, Barbara Tallman to interview your relative for the research project. Barbara Tallman is a Master's student in Nursing. This project is apart of the requirement for completion a Masters. She is examining the relationship between cognitive limitations, social ability and helping ability among individuals who experience cognitive changes.

Do you have any questions about this research project?

The research assistant will answer the questions. If he/she can not answer them, the research assistant will talk to the researcher and phone the family member back with the response.

If you agree that your relative can participate the next step is to sign a consent form.

Is there a convenient time when I or the researcher, Barbara Tallman could meet with you and answer further questions and sign the consent if you agree?

Note: If needed the research assistant can contact Barbara Tallman and she can phone the relative back.

Cognition, Social Ability, and Helping Behaviours Among  
Residents with Cognitive Limitations

**CONSENT FORM**

The purpose of the study is to gain an understanding of the relationship between the cognitive limitations (memory and spatial ability) experienced by residents and their social and helping abilities. The results of the study may be helpful to health professionals by providing insight into positive behaviours that continue in residents with cognitive limitations. The results may also help health professional consider strategies for supporting these positive behaviours.

The study is being conducted by Barbara Tallman, a Graduate Student, Faculty of Nursing, University of Manitoba, and will form part of the course work for the Masters Degree.

This consent provides your permission to approach your relative to be involved in this study and to collect information from the chart. Your relative will be involved in a face-to-face interview with Barbara Tallman. Barbara Tallman will ask questions that relate to depression, social ability, helping behaviour and cognition. The interview includes two instances where Barbara Tallman will create a situation that provides an opportunity for your relative to be helpful. The interview will take approximately one hour. Information will also be collected from your relative's chart. The information collected from the chart will include demographic information such as age, medical diagnosis, medications, education, ethnicity, religion, marital status, number of children, and the length of time that they have been at the facility. Other information collected from the chart will be on the client's ability to care for her own basic needs, their motivation, their memory, any discomfort that they experience, their mood and behaviour.

Participation is voluntary and if your relative indicates that she is not interested in participating either by not responding to the questions or by stating she is not interested, then Barbara will no longer attempt to involve your relatives in the study. The interview will also cease if the resident indicates fatigue, distress or agitation. If you decide to withdraw your relative from the study you may do so at any time. Withdrawing from the study will not impact on the quality of care that you relative are provided at this institution. You can withdraw by phoning and leaving message on Barbara Tallman's voice mail (phone numbers listed below).

The information that you provide will be kept confidential and only be known by the Barbara Tallman, a research assistant and the thesis supervisor, Lorna Guse. Confidentiality will also be maintained during the interview by conducting the interview

in the privacy of the resident's room. Findings from the research will be published but the data will be grouped with no individual identities.

There is no known risks involved with participating in the study. The study offers no direct benefits to you or your relative. You can receive answers to any questions about the study at any time by contacting Barbara Tallman.

Questions about the research and participation can be directed to Barbara Tallman at 788-8591 or 261-5968. The thesis supervisor is Dr. Lorna Guse and she can be reached at 474-6220. This research has been approved by the Nursing/Education Research Ethics Board at University of Manitoba. If you have any concerns or complaints regarding a procedure in this study, please contact the Human Ethics Secretariat (474-7122).

I agree that my relative can participate in the study "Cognition, Social Abilities and Helping Behaviours Among Residents with Cognitive Limitations".

Date: \_\_\_\_\_

Signature of Relative: \_\_\_\_\_

Signature of Resident: \_\_\_\_\_

Barbara Tallman/ Research Assistant: \_\_\_\_\_

A copy of findings will be available to you on request. Please indicate below if you are interested.

I am interested in receiving the results to this study.

I am not interested in receiving the results to this study.